UNDERSTANDING AND ADDRESSING LONG COVID AND ITS HEALTH AND ECONOMIC CONSEQUENCES

HEARING

BEFORE THE

SELECT SUBCOMMITTEE ON THE CORONAVIRUS CRISIS

OF THE

COMMITTEE ON OVERSIGHT AND REFORM

HOUSE OF REPRESENTATIVES

ONE HUNDRED SEVENTEENTH CONGRESS

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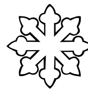

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UNDERSTANDING AND ADDRESSING LONG COVID AND ITS HEALTH AND ECONOMIC CONSEQUENCES

Tuesday, July 19, 2022

HOUSE OF REPRESENTATIVES
COMMITTEE ON OVERSIGHT AND REFORM
SELECT SUBCOMMITTEE ON THE CORONAVIRUS CRISIS
Washington, D.C.

The select subcommittee met, pursuant to notice, at 10:13 a.m., in room 2154, Rayburn House Office Building, and via Zoom; the Hon. James E. Clyburn (chairman of the subcommittee) presiding.

Present: Representatives Clyburn, Waters, Maloney, Velázquez, Raskin, Krishnamoorthi, and Green.

Also present: Representative Pressley.

Chairman CLYBURN. Good morning. The committee will come to order.

Without objection, the chair is authorized to declare a recess of the committee at any time.

I now recognize myself for an opening statement.

Our Nation has made tremendous progress in the fight against the coronavirus because of the powerful protection provided by widely available vaccines, treatments, testing, and other tools. Since President Biden took office, data shows coronavirus deaths have been reduced by 90 percent. The Administration's comprehensive pandemic response has shaped us to move beyond the crisis phase of the pandemic and focus on creating jobs, increasing wages, lowering costs, and taking other steps to help farmers emerge even stronger.

Even as we celebrate these accomplishments and work to continue our progress, many Americans, unfortunately, continue to suffer from a condition known as Long COVID, defined as experiencing symptoms beyond the time period of one's initial coronavirus infection. For a portion of these Americans, the symptoms have been severe, including chronic fatigue, muscle and joint pain, shortness of breath, and cognitive impairment. Some people's symptoms have lasted since 2020 and show no signs of improvement. There is still much we need to learn about Long COVID.

Researchers do not fully understand its risk factors, causes, and effects, which can manifest themselves in a variety of ways. Our Nation's scientists are working to develop methods to reliably diagnose Long COVID, and trials are underway to test new treatments. Today's hearing provides an opportunity to learn how we can support these research initiatives, guide healthcare workers, inform

the public about Long COVID, and provide support to affected Americans.

Researchers also have struggled to estimate just how many Americans have experienced and are continuing to experience Long COVID. An analysis by the Centers for Disease Control and Prevention of data collected by the Census Bureau over the first two weeks of June, estimated that 35 percent of American adults, who were ever infected with the coronavirus, experienced Long COVID. Nearly 1 in 5 of those who were previously infected were currently experiencing Long COVID symptoms at the time the survey was conducted. Some estimates are higher, but others are lower. Even if the lower estimates are the right ones, they still suggest that millions of Americans are experiencing this condition. It is not known what portion of those with Long COVID have experienced severe symptoms, but it is known that many report symptoms that interfere with their daily lives, making it more difficult to care for their families or fulfill the demands of their jobs.

Earlier this year, the Government Accountability Office estimated that 1 million Americans have been pushed out of work due to Long COVID. Many of these impacted families lose necessary income and employer-based health insurance at a time when they need it most. This takes a toll not only on those directly experiencing Long COVID and their families but also on a broader economy.

One study has estimated that the United States faces up to $3.7 trillion in economic losses from Long COVID, including approximately $997 billion in lost earnings from those who cannot work due to Long COVID and approximately $529 billion in increased medical spending. Communities of color have experienced a disproportionately high burden from the coronavirus, which has been compounded by longstanding health disparities and economic barriers.

Although research into the impact of Long COVID on vulnerable populations is ongoing, the recent CDC data suggests that women are more likely to be diagnosed with Long COVID than men and that Black and Hispanic Americans are more likely to experience Long COVID than white Americans. It is crucial that we improve our understanding of Long COVID on these communities so that all Americans receive equitable care, fair access to resources, and the best health outcome possible.

We are taking steps to better understand and address Long COVID and its consequences. Congress has provided the National Institutes of Health with more than a billion dollars for Long COVID medical research. The Biden-Harris administration has initiated a whole-of-government approach to address Long COVID and provide support for Americans suffering from the condition. The Administration has expanded access to Long COVID clinics across the country and bolstered health insurance coverage for Long COVID care.

President Biden also directed the Department of Health and Human Services to ensure to issue the first ever interagency National Research Action Plan on Long COVID by this August, which will include strategies to help measure and characterize Long COVID in both children and adults, foster development of new

treatments, and improve data sharing between agencies, academia, and industry researchers. These steps will help advance progress in prevention, diagnosis, treatment and provide greater support for affected Americans, considering the condition's disproportionate impact on different racial and ethnic groups and those with underlying disabilities.

HHS, in conjunction with the Department of Justice, has also issued guidance specifying that Long COVID qualifies as a disability under the Americans with Disabilities Act. This is an important step in ensuring that Long COVID is appropriately treated by employees, as a disabling event it can often be, and providing workers the protections they need so we do not have to choose between a paycheck and their health. Despite this progress, millions of Americans experiencing Long COVID and their families are desperate for answers and support.

Today's hearing will help clarify what is known about Long COVID, what is unknown, and what we can do to answer these critical questions. We already know we must take additional action to further accelerate research, increase workplace protections and accommodations, and ensure medical care treatment and benefits are accessible and affordable. I would like to thank our witnesses for joining us today and for sharing their expertise on what support and services we need to address this urgent public health and economic challenge.

Before yielding to the ranking member, I now ask unanimous consent that Representative Pressley be allowed to participate in today's hearing.

Without objection, it is so ordered.

Now in the absence of Mr. Scalise, our ranking member, I am pleased to yield to Dr. Green for an opening statement.

Mr. GREEN. Thank you, Mr. Chairman, and I want to thank our witnesses for being here today. I want to really appreciate your time and the energy it takes to prepare for a committee hearing.

Today's hearing is on a medical phenomenon where individuals infected with COVID experience lingering health conditions that may very well be related to their COVID infection. As a physician, I know it is important that we examine this closely to determine the linkage of symptoms and the ailments to COVID–19 and how best to treat such conditions. Without a doubt, many illnesses and injuries can result in intermediate and long-term effects, whether it is a viral disease, physical injury, or traumatic events. Reported symptoms of Long COVID have ranged from persistent fatigue, respiratory problems, brain fog, and cognitive impairment.

At this point, there is still much that we do not know about the cause, nature, and prevalence, and treatment of a course of this condition. This is especially true given the commonality of conditions such as fatigue, insomnia, anxiety, and concentration impairment, which may stem from a wide range of health conditions. And I am reminded of the challenge of determining the pathophysiology of chronic fatigue syndrome.

In 2020, Congress approved $1.15 billion for the NIH to conduct research on the risk factors and causes of Long COVID. Research studies are ongoing, and hopefully, those will shed new light on the nature, causes, and possible treatment of long-term COVID. Long-

term post-viral effects of COVID are a medical phenomenon that should be studied so that we can increase our understanding and ability to treat it. It is not an appropriate justification for yet another extension of a public health emergency.

COVID is now endemic. It is an endemic disease, and we need to treat it as such. Most Americans, as well as much of the rest of the world, have long since accepted that reality, and it is time for our Federal Government to do the same. Just last week, the Biden Administration decided to extend the public health emergency declaration for another three months, and who knows if they will extend it beyond that. While there may not be good scientific or medical reasons to extend the public health emergency declaration, there are quite a few political reasons.

Many of the Federal Government's pandemic-related waivers funding and temporary policy changes will end with the emergency declaration termination. For example, the public health emergency declaration prevents states from removing millions of ineligible recipients from their Medicaid rolls. As a result, it is no surprise that Medicaid enrollment has skyrocketed, going from 71 million to 95 million in just two years. Thirty percent of the Nation is now on Medicaid, even though many of these new additions no longer qualify for Medicaid because the only ways states can remove someone under the emergency is if they die or move out of the state.

In a lot of cases, millions of these Medicaid recipients have returned to work and have incomes above the Medicaid level4, and they would otherwise be getting health coverage through their employer instead of through the state. That is 30 percent of all Americans because the Federal Government is telling states that they can't enforce crucial eligibility requirements in their Medicaid programs during the public health emergency as a condition of additional funding. Keep in mind that Medicaid's improper payment rate is around 20 percent.

It is irresponsible and disingenuous for the Biden Administration to perpetually extend the public health emergency like it did just last week. It is long past time for this Administration to recognize that COVID has become endemic like all coronaviruses, and we can't keep governing with emergency policies indefinitely. Americans understand that we are past the emergency phase of COVID, and it is time for the Nation to return to normal.

Mr. Chairman, I would also like to seek unanimous consent to enter two articles into the record that I will discuss during my question period. The first is a study from the Annals of Internal Medicine about the sequelae and immunity baseline findings of a long-term COVID. I would like to enter that, if I could, in the record.

Chairman CLYBURN. Without objection.

Mr. GREEN. The second document that I would like to enter is from a group of physicians who have determined treatment mechanisms and modalities using FDA-approved treatments for other conditions. I will talk about it when I get my opportunity for questions and this mechanism that they are using as external counterpulsation therapy. I would like to enter that as well.

Chairman CLYBURN. Without objection.

Mr. GREEN. Thank you. Thank you, Mr. Chairman.

I look forward to our witnesses' comments.

Chairman CLYBURN. I thank Dr. Green for his statement. I would like to welcome today's witnesses. Dr. Monica Verduzco-Gutierrez is a professor and chair of the Department of Rehabilitation Medicine at the University of Texas Health Science Center at San Antonio. Dr. Verduzco-Gutierrez helped establish and now leads two Long COVID recovery clinics, where she treats patients suffering from Long COVID. Katie Bach is an expert on labor, job quality, and low-wage work. Most recently, she authored a report on the adverse effects of Long COVID on the labor market. Ms. Bach has previously served as the managing director of the Good Jobs Institute, founded by the Massachusetts Institute of Technology.

Hannah Davis is one of the founders of the Patient-Led Research Collaborative, an organization that facilitates patient-led and patient-involved research and advocates on behalf of Long COVID patients. Ms. Davis has offered several studies on Long COVID and has been a Long COVID patient since March 2020. Cynthia Adinig became an advocate for those suffering from Long COVID, particularly in marginalized communities, after becoming infected with the coronavirus in March 2020 and subsequently developing severe Long COVID symptoms. Ms. Adinig has shared her story in several national publications.

Will the witnesses please rise, those present, and all please raise your right hands? Will you please rise, and those joining us virtually, please raise your right hands.

Do you swear or affirm that the testimony you are about to give is the truth, the whole truth, and nothing but the truth, so help you, God?

[A chorus of ayes.]

Chairman CLYBURN. Let the record show that the witnesses answered in the affirmative.

Without objection, your written statements will be made part of the record.

Dr. Verduzco-Gutierrez, you are recognized for five minutes.

STATEMENT OF DR. MONICA VERDUZCO-GUTIERREZ, PROFESSOR AND CHAIR OF THE DEPARTMENT OF PHYSICAL MEDICINE AND REHABILITATION, DIRECTOR OF COVID RECOVERY CLINIC AT UNIVERSITY HEALTH, UNIVERSITY OF TEXAS HEALTH SAN ANTONIO

Dr. VERDUZCO-GUTIERREZ. Chairman Clyburn, and honorable members of the Select Subcommittee on the Coronavirus Crisis, thank you for inviting me to speak today. My name is Dr. Monica Verduzco-Gutierrez. I am professor and chair of Rehabilitation Medicine at the University of Texas Health Science Center at San Antonio. I am approaching my testimony from the perspective of a physical medicine and rehabilitation physician who specializes in brain injury medicine and who now runs two COVID recovery clinics in San Antonio, Texas. Before the pandemic, the patients I cared for had brain injuries or strokes, but now I care for an expanding new population of patients with Long COVID, and I will be asking you to ensure they get the access to care and research that they need.

In August 2020, I saw my first patient with Long COVID. Many of them are frontline workers and public servants. Almost 500 patients later and each one has their own battles with Long COVID: patients who have developed an autoimmune disease, who can't stand up for two minutes without their heart rate going up the roof, who have fatigue 100 times worse than when they had cancer, marathoners who can't run, healthcare providers who can't physically or cognitively return to the bedside. And no matter the variant, no matter the severity, no matter the age or prior health of the patient, COVID is impacting millions of Americans.

And still, since almost two years ago, there is not a way for me as a physician to diagnose Long COVID based on a physical exam, bloodwork, an EKG, or a scan, and the patients keep coming. Some patients are waiting upwards of six months to be seen. For some of them, when the day of their appointment arrives, some don't make it, not because they got better, but because they got worse. They lost their job and healthcare insurance, or they are so disabled, they can't get out of bed. I am told it is a full-time job using all their resources just to feel OK. So many cannot work.

I see patients who are both affluent and those who are in the safety net system. The most vulnerable with the most barriers to access to care will be at increased risk of disability and poor outcomes. As the popular song says that you might have heard a few months ago from your grandkids or children, "We don't talk about Bruno, and we don't talk about the brain with COVID."

Research is emerging that COVID–19 can cause immune-mediated neurovascular injury and, therefore, neurologic complications. When disease-caused brain inflammation goes undiagnosed, there can be huge consequences. Many of my patients have overlapping symptoms with those seen after brain disease: memory loss, concentration problems, insomnia, headaches, dizziness, tremors, dysautonomia, anxiety, PTSD, and suicidal thoughts. Some have even experienced rapid dementia.

I have collaborated with my local experts at U.T. Health San Antonio's Biggs Institute for Alzheimer's and Neurodegenerative Diseases. The institute is now a National Institute on Aging designated Alzheimer's disease research center, 1 of 33 nationally and the only one we have in Texas.

I came from a very humble background in South Texas, but I went into medicine for the same reason you went into public service. We are here to help people, all people. My national society, the American Academy of Physical Medicine and Rehabilitation, has developed a host collaborative of 40 clinics. We treat patients around the country and in some V.A.s as multidisciplinary teams. We take hours with patients and have published clinical guidance statements, but we are seeing enormous resource strains. Action needs to be taken to support the healthcare work force for these clinics along with the research and the treatments.

We need to reconfigure our approach to post-viral diseases that are historically underfunded. We need to talk about post-viral illnesses. We need to talk about the perfect storm of brain inflammation and an immune system gone awry. And we need to study the overlap of people with myalgic encephalomyelitis, chronic fatigue

syndrome, and other post-viral illnesses. This is a public health crisis.

I would choose this path as a physician 1,000 times over. As I advocate for patients with Long COVID, I can only do so much as I see one at a time, but you can help more. Congressional action is needed to ensure that individuals with Long COVID can access the care they need. Pending legislation is there—treat for Long COVID Act, CARE Act, Cures 2.0 Act, COVID-19 Long Haulers Act—would address numerous hurdles.

Thank you so much today for this opportunity, and I will be happy to answer your questions.

Chairman CLYBURN. Well, thank you, Dr. Verduzco-Gutierrez.

Dr. VERDUZCO-GUTIERREZ. Perfect.

Chairman CLYBURN. Thank you very much. The chair will now hear from Ms. Bach. You are now recognized for five minutes.

STATEMENT OF KATIE BACH, FORMER MANAGING DIRECTOR, GOOD JOBS INSTITUTE

Ms. BACH. Good morning. My name is Katie Bach. I am a nonresident senior fellow at the Brookings Institution, where I have been writing on the labor market impact of Long COVID.

Despite being two-and-a-half years into the pandemic, we still know far too little about Long COVID: why people stay sick, how long they stay sick, or what the impact is on their lives. Yet we are gaining an understanding, albeit incomplete, of the economic impact of Long COVID. Specifically, it is somewhere in the neighborhood of 4 million Americans are not working due to Long COVID. Today, I will explain that number, give a brief sense of the overall economic impact of the disease, and discuss mitigation measures.

So first, to understand how many people are out of work with Long COVID, we need to know how many people have it. Last month, the Census Bureau's Household Pulse Survey added four questions on Long COVID prevalence and found that about 8.1 percent of working-age Americans currently have Long COVID. That is about 16.4 million people, and I want to note that a recent Federal Reserve Bank of Minneapolis study corroborates this figure using longitudinal survey data. But not everyone with Long COVID will leave work or reduce their hours. Mild symptoms, employer accommodations, or sheer financial need can keep people employed. But in many cases, Long COVID does impact work, and studies on the percentage of long haulers whose work hours are impacted vary substantially, from about 25 percent to 65 percent. So using a very conservative estimate at the absolute lower end of that range gives us about 4 million full-time equivalent workers out of work due to Long COVID.

To give a sense of the sheer magnitude of that number, that is about 2.4 percent of the U.S. employee population. Unfortunately, this number appears likely to increase. The most compelling study I have seen on vaccines in Long COVID suggests that vaccines reduce the risk of Long COVID by only about 15 percent. And while we don't yet know definitively the Long COVID risk of repeat infections, a recent study found that every repeat infection does increase the odds of long-term health consequences of COVID–19.

So as we see more infections and more reinfections, we are likely to see more Long COVID cases. And to put this in perspective, consider the economic cost of just the lost earnings of long haulers. This does not include lower productivity of people working with significant healthcare costs incurred by patients, cost productivity of caretakers. So just the loss earnings of the long haulers is about $230 billion a year, given the U.S. average wage. And I will just note that this ties almost exactly to the figure that we heard the beginning, the 1 trillion figure. So if the Long COVID population increases just 10 percent each year, by 2030, we will be incurring a lost wage cost of about $500 billion a year.

So to mitigate the economic drag of Long COVID, policymakers should support five interventions. First, as we just heard, we need better treatment and prevention. We need better research to inform better and more accessible options. Second, we need universal access to paid sick leave. Currently, about 30 million private-sector workers do not have any form of paid sick leave. That means they are more likely to go to work sick and spread COVID–19, which leads to more reinfections and more Long COVID.

Third, we need access to Social Security Disability Insurance benefits. Reports suggest that Long COVID patients are struggling to secure approval for SSDI. To change that, Congress could expedite the approval process for Long COVID patients, make it easier for those patients to secure approval, and critically waive the 24-month waiting period for Medicare benefits for SSDI recipients so that these people can access care. Fourth, we need improved employer accommodation. One of the paradoxes of the pandemic is that while the number of disabled Americans has risen significantly, the share of disabled Americans working has also increased. That is likely because of the shift to remote work, and it is a testament to the power of employer accommodations to keep people productive.

Finally, and critically, we need better data collection. To fully assess the labor market impact of Long COVID and to track the efficacy of interventions, the Bureau of Labor Statistics and the Census Bureau should introduce questions about Long COVID's impact to the HPS as well as to the current population survey.

I thank the subcommittee for the opportunity to testify today, and I look forward to hearing your questions.

Chairman CLYBURN. Thank you, Ms. Bach. We will now hear from Ms. Davis. Ms. Davis, you are recognized for five minutes.

STATEMENT OF HANNAH DAVIS, CO-FOUNDER, PATIENT-LED RESEARCH COLLABORATIVE

Ms. DAVIS. Thank you. My name is Hannah Davis, and I am a co-founder of the Patient-Led Research Collaborative.

I got COVID in March 2020. Two years later, I still have cognitive dysfunction, memory loss, nerve damage, clotting markers, immune system dysfunction, dysautonomia, which is a dysfunction of the autonomic nervous system, and ME/CFS, a disabling complex neuroimmune condition. I still have difficulty driving, reading, and walking, and I still have not recovered. Before I got sick, I worked in artificial intelligence, but I haven't been able to return

to that kind of work. I am considered a mild case by every definition.

We know a lot about Long COVID. It's a complex biomedical condition spanning multiple organ systems, happening after 20 percent of COVID cases. Research to date has found microclots, poor cerebral blood flow, dysfunction of blood vessels, ongoing immune dysfunction, disruption to the blood-brain barrier, connective tissue issues, and hundreds of other findings. Major theories about Long COVID's cause include viral persistence, clotting issues, neuroinflammation, immune dysregulation, microbiome changes, connective tissue damage, and hypermobility-related issues, autoimmunity, or a combination of these.

Last month the U.S. Census released data showing an estimated 7.5 percent of all U.S. adults currently have had Long COVID for at least three months. Women and socioeconomically disadvantaged patients are most at risk, though every demographic is affected. Not being able to rest increases the risk and severity of Long COVID, which means people without appropriate work accommodations and those who must continue household or caretaking labor are at increased risk, as is anyone without documentation of a COVID test who cannot substantiate or does not know their need for rest.

Lack of public education has led to many misunderstandings about what Long COVID is. Seventy-six percent of cases happen after a mild onset. Many did not have respiratory symptoms or low oxygen levels. Many people assume Long COVID is a continuation of COVID's acute symptoms when it is a new onset of multisystemic symptoms. A delay of weeks or months often happens between COVID onset and Long COVID and is more likely in younger adults. Long COVID can happen after reinfection in those who fully recovered from their first infection. Vaccination slightly reduces the risk of Long COVID, but it still happens often in fully vaccinated people with one study showing nine percent of triple vaccinated people got Long COVID after Omicron BA.2.

Over half of Long COVID patients develop ME/CFS, dysautonomia, or both. ME/CFS is one of the world's most disabling illnesses with a quality of life worse than end-stage renal failure, cancer, and stroke. Seventy-five percent of people with ME/CFS can't work, and 25 percent are bed bound. Only five percent recovered.

Consistent abnormal findings in ME/CFS include T-cell exhaustion, mitochondrial dysfunction, deformed red blood cells, exercise intolerance, altered brain function, and reactivated viruses. Only six percent of med schools fully teach post-viral conditions, like ME/CFS, and few providers and researchers are familiar with them. There are two dozen ME/CFS experts in the U.S., but little collaboration with our funding them, and we are wasting time reinventing the wheel with research exploring hypotheses that were disproven decades ago. Similarly, many providers and some Long COVID clinics don't know that outdated treatments, like graded exercise therapy, can cause patients with ME/CFS to worsen and become bed bound. Misconceptions around PCR and antibody tests have caused issues in research and care. These tests are often re-

quired for sick leave, entry into Long COVID clinics, healthcare, and participation in research.

PCR tests have high false negative rates, however, and are less accurate in women and people under 40. There is also widespread misinformation that everyone who gets COVID makes antibodies, but a quarter of people don't make detectable antibodies, and others lose them over time. Both scenarios are more likely in women and those with initially mild illness. Additionally, multiple studies show a lack of antibody creation may actually be a feature of Long COVID and can be used to predict Long COVID. This information is not widespread, however, and many studies include antibody-negative Long COVID patients and control groups, leading to inaccurate results.

Long COVID must be considered in every step of the COVID response. It has already impacted our work force. Many people with Long COVID can't work or need reduced hours, and struggle to apply for disability benefits. The financial impact is devastating and cannot be overstated. Long COVID will destroy our economy and disable a huge percentage of our society if we do not decrease new cases and prioritize a cure for existing ones.

We need eight immediate actions: an urgent public information campaign on Long COVID to explain that it happens after mild cases and requires immediate pacing and rest; prevent transmission, including through mask mandates and widespread ventilation; provide paid leave to rest during acute COVID; reform SSI and SSDI to shorten processing times, increase benefits, remove waiting periods, update asset limits; and provide free legal assistance to those applying; provide financial assistance to the millions of long haulers unable to pay their daily costs of living; fund current post viral experts and let them lead Long COVID research; expedite and fund clinical trials, including anticoagulant therapy, antivirals for both COVID and reactivation, like EBV, and trials for ME/CFS and dysautonomia, including mitochondrial treatments, IVIG, and connective tissue restoration; and expand and improve clinical care, including education on ME/CFS and dysautonomia.

Thank you.

Chairman CLYBURN. Thank you very much, Ms. Davis. We will now hear from Ms. Adinig. You are recognized for five minutes.

STATEMENT OF CYNTHIA ADINIG, LONG COVID PATIENT AND ADVOCATE

Ms. ADINIG. Good afternoon, Chairman Clyburn, and members of the Select Subcommittee on Coronavirus Crisis. I am grateful for the honor and privilege it is to be here. My name is Cynthia Adinig, and I never expected to be here, disabled and speaking on behalf of a growing number of community of millions from across the Nation.

Before I got sick in the first wave, I was a multitasking supermom and entrepreneur. I ran two businesses, volunteered at my church and multiple charities while homeschooling my young son. Unfortunately, I can no longer serve or work in the capacity that I used to because from time-to-time now, my body becomes overwhelmed with nausea, dizziness, intermittent paralysis, crippling joint pain, and unexpectedly high heart rate to the point I

fear I am having a heart attack or a stroke. I also currently have a seven-year-old genius son who suffers from Long COVID.

The summer of 2020 was many, many trips in a hospital, and I was dying. I lay awake at night every night thinking mournfully about the very real potential my son will grow up without a mother. As my struggle to recover continued, I was unexpectedly thrust into advocacy stemming from a blatant racially biased incident in September 2020. While being a wheelchair-dependent person at the time, I was threatened with arrest by emergency room hospital staff while seeking medical help during an episode of dangerously low oxygen and high heart rate. The same hospital had tested me for illicit drug use without my knowledge 3 times prior in response to the Long COVID symptoms I presented with. In spite of my negative drug tests repeatedly coming back negative for illicit drug use, I was even slated to be given Narcan for withdrawal during one of my admissions for Long COVID. Yet without apology, this hospital now touts itself as a post-COVID rehabilitation center.

I am standing here today thanks to a heavy regimen of medications, but I still remain disabled, chronically ill, and under treated. Unfortunately, my last trip to the emergency room from Long COVID just two weeks ago remained startling reminiscent of my care two years ago as it produced little more than this bruise from my IV of fluids. Though I went to the hospital with symptoms common for myself and others stemming from Long COVID, I wasn't administered any medication, nor was the protocol for my diagnosed symptoms followed. As I stiffly hobbled out the hospital at the crack of dawn, I caught an Uber home, mulling over the harsh reality that efforts and advocacy thus far has resulted in little visible progress in education of medical staff concerning Long COVID. I am currently tasked with a monitoring my son's vitals daily, with little hope of getting him care for his intermittent struggle of an elevated heart rate, blurry vision, and fatigue, as there are very few experienced post-viral pediatric specialists in the Nation.

I know my mention of race in regards to Long COVID care will make some of those watching this hearing defensive. However, it is clear through unbiased studies and historical records that race and gender play a major part in hurdles in American healthcare. Some who listen may even rebut that my mention of racism is a means to divide and provoke. A select few may even say I should simply be happy with the current level of Long COVID healthcare in America, that my privilege of standing here before you should be enough. But to quote Martin Luther King, Jr, "I criticize America because I love her."

I can proudly say that I know we as Americans, including yourselves as Members of Congress, can come together in addressing Long COVID, as I owe much of my recovery to many in the ME/CFS community, former complete strangers, such as Ashanti Daniels, Wilhelmina Jenkins, and Rivka Solomon, who heard my story and leaped to act.

Long COVID is projected to directly affect over 20 million within our Nation, and the strain it puts on our economy and working families is far greater. I am asking that our Members of Congress come together and pass the CARE for Long COVID Act, to create an official COVID–19 victims and survivors memorial. And I ask

you to please permit to making a Federal standardized disparity index system for medical centers. I don't ask you this to do this for me and the future of my precocious bright son, but also in remembrance of over 1 million lives lost to COVID and for every American family that has been impacted by this pandemic.

Thank you.

Chairman CLYBURN. Well, thank you very, very much. We have now heard from all of our witnesses and each member. We will now have five minutes for questions.

The chair recognizes himself for five minutes.

Ms. Adinig, we have just heard from your opening statement that you have suffered from severe and often debilitating Long COVID symptoms over the past two years. Adding insult to injury, you have shared with us in your statement medical professionals are not taking your symptoms seriously. Now, not many of us have had that experience of not being taken seriously or being disbelieved. Could you share a little more as to what that experience is like?

Ms. ADINIG. Absolutely. It has been a traumatic experience. I came into the healthcare system thinking that I was going to a safe space, a space where I would receive help. But week after week, as I starved as Long COVID has caused me to develop a severe allergic reaction to all food and water, I starved for weeks to the point that I ended up in a wheelchair. I knew I was dying. I begged for help from several hospitals, and no one listened; and I was terrified that I would not see my son's fifth birthday. And in spite of that, I still have to go back to those same spaces for care in hope that maybe this time they will listen, but sadly, in spite of my diagnosis of Long COVID MCAS, POTS, dysautonomia, multiple chemical sensitivity.

Chairman CLYBURN. Now, you know this, but I just want to reiterate that you are not the only one suffered from Long COVID. We have experienced this doubtful questioning.

To illustrate that point, I ask for unanimous consent to enter into the record a statement that this committee has received from Senator Tim Kaine, who has been suffering from Long COVID since March 2020.

Without objections.

Chairman CLYBURN. Senator Kaine writes, "For the last two years, I have experienced constant nerve tingling, which feels like every nerve in my body has had five cups of coffee." After Senator Kaine began to share his non-COVID experience publicly, he heard stories from many others suffering from the condition and struggling to be taken seriously. He further writes, "Many who shared their Long COVID stories with me felt that they were not being believed by the medical community or that their symptoms were being misdiagnosed and mischaracterized as anxiety or depression."

Ms. Davis, I understand that you have also been affected by Long COVID and have worked with many other Long COVID patients through advocacy. What can Long COVID patients like Ms. Adinig, and Senator Kaine, and yourself do to educate medical professionals and the public at large about the real sufferings and struggles you are facing?

Ms. DAVIS. I mean, I think that you know, we are all doing as best we can. But really, there needs to be a large-scale education program, both for the general public about what Long COVID is, about confronting a lot of these misconceptions about what Long COVID is, communicating that post-viral illness happens after almost every virus from mono to Ebola, to West Nile. You know, we learned just last year that the EBV virus can cause multiple sclerosis decades down the line. We know that HPV leads to cervical cancer. We should have expected this. We know from the last SARS that 27 percent of SARS–1 survivors had almost exactly the same condition that we are all suffering. So we really need a large-scale education program of the public and medical providers.

Chairman CLYBURN. Well, thank you very much. The chair now recognizes Dr. Green for five minutes.

Mr. GREEN. Thank you, Mr. Chairman, and again, thanks to our witnesses. I appreciate everyone's comments.

First, I would like to address the submission I had from a group of clinicians who have discovered a mechanism external counterpulsation and FDA-approved treatment that seem to be working for Long COVID, particularly the pulmonary symptoms of it. And the point I want to make here is that during this COVID response, the government has come in and restricted a lot of what physicians can do, and it is the clinical decisionmaking of doctors that are making a difference.

And I was impressed by your testimony and what you are doing, Dr. Verduzco-Gutierrez. I really appreciated your statements. We can't let the government dictate physicians and take away their clinical judgment. It is a tragedy, but if you look at what California is doing, it is unbelievable, and we need to let doctors be doctors. I think that is ultimately the point I was making with that.

I also submitted an article from the Annals of Internal Medicine, one of our country's most revered medical journals. This ongoing longitudinal study conducted and funded by the NIH examined a cohort of patients in an effort to better understand the long-term medical consequences of COVID infection. The study, in addition to examining medical history, symptomatic issues, conducting diagnostic evaluations, echocardiograms, bloodwork, and neurocognitive assessments on the patients. In other words, it is a pretty robust clinical study looking into the causation and physical manifestations of Long COVID.

Upon clinical examination of a wide range of biomarkers and variables, the study did not find meaningful variations between those with PASC, the clinical term for Long COVID, and those without it. In fact, the study did not find evidence to support some of the commonly suggested causes of Long COVID, such as an abnormal immune response, ongoing organ damage from COVID–19, and inflammation. In short, the initial observation of this clinical investigation have not demonstrated clear pathogenesis. That doesn't mean the issue doesn't exist. That is important to differentiate here, but it did not find a pathogenesis arising from prior infection. So the precise cause of these symptoms is still not yet understood. Of course, as I mentioned in my opening statement, additional research is needed to gain a sound medical understanding of

this and advance our ability to treat these patients presenting with the symptoms following COVID infection.

And my first question is to the Doctor, who is here with us today. Two questions. You know, first, what are the clinical criteria that you use to make the diagnosis of long-term COVID?

Dr. VERDUZCO-GUTIERREZ. The clinical diagnosis that I use is. First, we don't have a great diagnosis, and there are several different, you know, whether you look at the World Health Organization, the NIH, you know, there is inconsistency. But part of my evaluations, I see the patients. I listen to the patients, you know. Some of them did not have a positive test, some of them didn't make antibodies, but do they have a history of a likely infection with the coronavirus. And then they have ongoing symptoms that consist of, I mean, in some of the research, including the one led by Hannah Davis is, you know, 200 types of symptoms that are ongoing and just trying to address each of those symptoms when I see them.

Mr. GREEN. So I guess, as I understand, there is no real established criteria to make the diagnosis that physicians have agreed on or clinicians have agreed on. My other question is, are there other encephalopathies? And I know you are treating the brain impact in your PM&R practice. Are there other encephalopathies out there that we could be missing? For example, if we think this range of 200-plus symptoms, are we missing something if we say, hey, this must be Long COVID? Is the possibility out there?

Dr. VERDUZCO-GUTIERREZ. We need more research to look into it to say, you know, is there something else that we are missing?

Mr. GREEN. OK. To your knowledge, as a physician and researcher, what do you think is the likelihood of a person who has had a case of COVID that did not require hospitalization going on to have Long COVID? How many of your patients were not hospitalized on their initial COVID infection but have developed Long COVID?

Dr. VERDUZCO-GUTIERREZ. The beginning few months, probably the first siz months when more patients were hospitalized, only 25 percent had been hospitalized. At this point, where a lot fewer patients have been hospitalized, probably five percent or less have been hospitalized.

Mr. GREEN. Mr. Chairman, I think my time is up.

Chairman CLYBURN. Thank you. The chair now recognizes Ms. Waters for five minutes.

Ms. WATERS. Thank you very much, Mr. Clyburn, for this meeting on this subject. I have been reading as much as I possibly can about Long COVID, and it seems as if, once again, the vulnerable populations in this country, who have not had access to healthcare, who have not been part of the research that is being done or should be done, are at great risk. And so I believe that with the limited information that we have, that certainly Long COVID exists, and certainly, there are those who are severely impacted by it. Many of those will not be able to work continuously. They will be disabled.

And so, again, we don't want to make the same mistakes that we made, missing these vulnerable populations and not getting the vaccinations or the testing done in a timely manner. So this is an

important issue, and we must move very aggressively to try and make sure the research is done, and it is done with all of the vulnerable populations that might get missed and not get treated.

Having said that, Ms. Adinig, I want you to know that from the information that I have read, that those who perhaps have Long COVID can experience all kinds of symptoms, and it is not consistent with 1 or 2. It may be 3, 4, or 5. And even though I am looking at some of the information that I have, it does not include what it does in severe headaches. I don't see that information here. Also, I think that it affects, I am, told the eyes, et cetera, et cetera.

Now, having said this, and the question that was just asked about my colleague here about, you know, are there some factors that you need to see in order to be able to diagnose. And I think what you have said to us, Doctor, pretty much so, is that lots of research needs to be done, and there are no exact facts of symptoms that can determine that you have it or you don't have it, et cetera.

And so you know what that is going to mean when people are disabled, and they try and get support so that they can have a decent living, a decent quality of life? They are going to get turned down. They are going to be suspected of not telling the truth. They are going to be ignored. And so this is a problem. This is a big problem, and a really big problem being that we expect that there are new variants, B.4 and B.5, that will be actually operating in the very near future if it is not already operating as a variant. They complicate COVID–19.

And so I appreciate your testimony and you sharing with us what you have experienced and what you are going through. I appreciate all of those who are here today, giving us the information that you have. But I think that those of you in the medical community are going to have to be our best advocates. You are going to have to say to those who have the responsibility but give support to Long COVID victims that we cannot second and third, and fourth guess what they are telling us. Do all the testing that you can do. If the complications are there, some of them can be seen, some of them can be detected, but not all of them. And I came in a little bit when Mr. Clyburn was talking about something that somebody had described as going through their body that felt like it was worse than having multiple cups of coffee.

Chairman CLYBURN. Senator Kaine.

Ms. WATERS. Senator Kaine. Is that who it was? So I thank you again. I don't really have questions because, you know, there are so many questions. And so, just alerting us and, you know, saying to us, this is enough for me based on what I have learned. So thank you for being here today, all of our witnesses that are participating here. And, again, to doctors and our medical community, you are going to have to be our best advocates. You are going to have to tell about the complications as you encounter them. Thank you very much.

Chairman CLYBURN. Thank you, Ms. Waters. The chair now recognizes Mrs. Maloney for five minutes.

Mrs. MALONEY. Thank you, Mr. Chairman, and thank you for this incredibly important and informative hearing.

People with Long COVID face many hurdles, as we heard today, accessing care and the benefits that they deserve, and I did not realize until this hearing what a terrible disease it is with lingering challenges. There is no single test to diagnose Long COVID, and some physicians may dismiss Long COVID's wide variety of symptoms or attribute them to other health problems, which was another concern. So I would like to ask Dr. Gutierrez, in your clinical practice, what are the greatest challenges in assessing whether someone has Long COVID and providing treatment?

Dr. VERDUZCO-GUTIERREZ. Thank you very much. The greatest challenges are, first, access to care, so getting patients to be seen in the clinic, and then once the patients are being seen in the clinic, then getting them some of the tests. There are tests that are being done in research right now. We know that certain research is showing maybe patients may have micro clots or they may have abnormal immune markers that I cannot check on a regular test from a lab company or that our pathology office doesn't have the microscope to look for micro clots. So there is, again, difficulty finding diagnoses. And then also, that is why I feel it is best to work with multidisciplinary care because there are so many organs and body systems that can be affected in a single patient, as you have heard from these witnesses today, that it is best if it is done together with a cardiologist, a pulmonologist, or neurologist, rheumatologist, et cetera. And that type of multidisciplinary organized care is also very difficult to get, expensive care to get and can be a barrier for many.

Mrs. MALONEY. Now is there a test now to diagnose that someone has Long COVID, because I was told there was no test for it, and they are leaking papers. Dr. Gutierrez?

Dr. VERDUZCO-GUTIERREZ. No, ma'am, there is not.

Mrs. MALONEY. There is not. OK. What is the status of getting one? Are they researching it or——

Dr. VERDUZCO-GUTIERREZ. It is being worked on. There are investigators in the community across the world, and then they are working through the NIH RECOVER trial as well. Not coming fast enough.

Mrs. MALONEY. Reclaim my time. Some Long COVID patients are required to show proof of a positive coronavirus test in order to receive care, even if they get sick in the early days of the pandemic before the tests were widely available. So I have heard that some people may have Long COVID, and yet they don't have symptoms right now of COVID, so it is hard for them to get care. Can you address this, Ms. Davis? How can the lack of a Long COVID diagnosis affect the ability to obtain treatment and support for people who should be eligible for government benefits?

Ms. DAVIS. Yes, absolutely. That is one of the biggest issues we faced, particularly those of us in the first wave. I think one thing that is not very commonly known is only three percent of cases from the first wave had PCR documentation by the CDC numbers, and throughout the pandemic, only 1 in 4 cases are documented by PCR. So that actually is the majority experience, that you don't have a PCR documentation. And with the rise of at-home testing and rapid testing with nowhere to really report, that has increased more recently as well.

And so, there has been a tremendous bias toward people who have access to test accessibility, who had private healthcare in the beginning of the pandemic, or who had connections with medical providers, et cetera because for a very long time and still to this day, Long COVID clinics require a PCR test. And there has been some movement to doing antibody tests, which has actually made it worse since there is a huge gender bias against who makes antibodies. About a quarter to a third of people never make antibodies after a COVID infection. That is more likely if you had a mild case. It is significantly more likely if you are a woman. And of everyone who loses antibodies, which most often you lose antibodies in the first couple of months, 80 percent of people who lose antibodies are women.

So you have all of these Long COVID patients trying to get into these clinics, trying to get proof of PCR antibody tests, and the vast majority of patients who can't get into these clinics are socioeconomically disadvantaged patients and women. So it is causing a huge bias in terms of healthcare, and that also has ongoing implications for research.

Mrs. MALONEY. Well, my time has expired, and it shows a tremendous impact on Long COVID on women, and we need to get more information. Thank you all for your testimony. Thank you, Mr. Chairman, and I yield back.

Chairman CLYBURN. Thank you, Mrs. Maloney. The chair now recognizes Ms. Velázquez for five minutes.

Ms. VELÁZQUEZ. Thank you, Mr. Chairman, and thank you all for your great testimoneys and insight into this important issue.

Ms. Bach, women, and the community of color faced unique economic threats from Long COVID because they are over-represented in low-wage jobs that are challenging for workers with long-term health conditions. And these jobs typically lack crucial benefits, such as paid medical leave. Ms. Bach, how does a failure by employers to provide paid medical leave to exacerbate the harms of Long COVID?

Ms. BACH. Thank you for the question. I will admit this is an issue that has been top of mind for me. The burden on the most vulnerable workers is, as it often is, the heaviest. There are a number of reasons. One is disproportionate exposure to COVID in the early days of the pandemic when many of these low-wage workers were classed as essential workers. Two is the lack of remote working options, which means that they do have to be at work, and three, of course, is sheer financial need.

When you are making $20,000 a year, the difference between working and not is really life or death. So the failure of employers to provide paid sick leave has at least two pretty significant consequences. The first is people go to work sick, and when they go to work sick, they are more likely to give other people COVID, right? It is a failure of infection control. You see increasing numbers of infections because people can't afford to stay home. The second is it means that when people are sick, they push through because they don't have another choice. I am not a medical professional. I have heard anecdotally that the worst thing you can do when you have COVID–19 is to fail to rest. And unfortunately, a lot of these low-wage jobs, if we think about things like, you know,

certified nursing assistant, retail worker, food service worker, these are very physically demanding jobs.

Ms. VELÁZQUEZ. Thank you for your answer. Ms. Davis, based on your research, can you please explain how symptoms of Long COVID make it more difficult for affected individuals to work full time?

Ms. DAVIS. Absolutely. We found that cognitive dysfunction and memory loss was one of the most common symptoms, and that happened to around 90 percent of Long COVID patients and persists for a very long time. A lot of symptoms improve over time, like including respiratory symptoms. The cognitive functioning symptoms do not, and we ask basically how they impact people's lives, and it impacts work primarily. It impacts work the most, concentrating, but also talking to people, communicating information, and receiving communication. A lot of people have audio processing issues.

It also impacts watching children. It impacts driving. Over half of people with brain fog said that they were unable to drive in some capacity. That is true of myself. It really prevents you from participating in the world. It truly does feel like mild dementia. I had ADHD before I got sick. It is not like cognitive impairment. It really is disruptive to every avenue of your life.

Ms. VELÁZQUEZ. Thank you. And Ms. Bach, can you please explain the need for employers to recognize Long COVID as a disability and what can we do to provide information that will make them aware of an issue?

Ms. BACH. Yes. So I think there are two things. One, workers need to be aware that Long COVID is a condition that is covered under the ADA, and I think the government could do a lot to raise that awareness among workers. Second, employers not only need to be made aware that Long COVID is covered under the ADA. It would be helpful for employers to see examples of what Long COVID accommodations can look like in various industries. So for example, bringing together a group of employers who have made these accommodations, who have seen the productivity boost, which you absolutely will because once you hold onto workers and having them explain the types of accommodations they are making, I think it would be very valuable for the private sector as a whole.

Ms. VELÁZQUEZ. And can you please, Ms. Bach, explain what efforts Congress should consider to protect Americans struggling with long-term COVID?

Ms. BACH. Yes. I mean, No. 1, more investment in research because the best thing we can do is avoid people getting sick and help them get better. No. 2 better access to Social Security Disability benefits. Right now, people are getting denied all over the place because there is no objective test. No. 3, get rid of the Medicare waiting period for the SSDI recipients so they can access care. And No. 4, really invest in helping employers understand that they are legally obligated to make these accommodations, and it is to their benefit to do so.

Ms. VELÁZQUEZ. Thank you. Mr. Chairman, I yield back.

Chairman CLYBURN. Thank you very much. A vote is on, but I think we have got time for one more question there.

The chair now recognizes Mr. Raskin for five minutes. We will get two more questions.

Mr. RASKIN. Mr. Chairman, thank you so much for this very important and shocking hearing. Ms. Bach, I wanted to ask you some questions. I was moved by your testimony where you tell us there are an estimated 60 million working-age Americans who have Long COVID and 4 million who have a reduced or just vanquished ability to work at all, and that these numbers are likely to increase as more people get infected. So tell us, overall, you are an economist?

Ms. BACH. No, not really. I am an ex-management consultant, so I do a lot of analytics work.

Mr. RASKIN. All right. Well, what is your estimate of whether Long COVID is actually going to have an impact on the American economy? I mean, does this problem have enough magnitude actually to affect the economy generally?

Ms. BACH. So it does. I mean, as you all in this room know better than I, when we see a 0.5 percentage point decrease in the labor participation rate, this is front-page news. What I am talking about is the number of people out of work that is equivalent to 2.3 percent of the entire American employee population, so this is a huge number. And as I mentioned, what that does not take into account is the lost productivity of people who are still working but they are working sick, as Hannah said. So there is essentially no way this could not have a significant impact on the economy.

Mr. RASKIN. Right. So I am not quite sure the different mechanisms you have used to make these estimates, but what kinds of data collection are actually necessary for us to get a more definite hold on the problem?

Ms. BACH. Yes, this is a great question. When I originally wrote my Brookings piece about this, the whole point of the piece was to call for better data collection. So the two places where I would be collecting data to understand the economic impact are the Household Pulse Survey and the Current Population Survey. The Household Pulse Survey did just add four questions on Long COVID prevalence, which is fantastic, and that is where I started with my estimates. But then they need to ask questions about Long COVID duration and Long COVID impact on work.

The advantage to using the Household Pulse Survey is it is quick. We can get these questions essentially in the next wave. Might be a slight exaggeration. The Current Population Survey, on the other hand, is extremely statistically robust, and it is longitudinal. And so the advantage to using the Current Population Survey is you can track this over time with a high degree of accuracy, again, lead questions on prevalence and impact on work.

Mr. RASKIN. Yes. We have had this conflict ever since our committee began. Really, ever since COVID–19 was upon us, we have had a conflict between those who have tried to insist upon very strict public health protocols, masking, pressing for vaccination, and so on, and then a kind of laissez-faire, pro-herd immunity philosophy. We saw that in Deborah Birx's before the committee and in her book where she wrote about that split within the Trump administration, where she was trying to stick with the more traditional, you know, CDC science guidelines versus those things. "Just let it wash over the population." "We will lose some people." We ended up losing over a million people so far, but that is really the only thing that is going to work.

But your points or the points coming out in the whole hearing today suggest this is not only a dangerous strategy from the standpoint of people who are really vulnerable to it, but it is also dangerous to some random cross-section of people who are going to end up with Long COVID. And that doesn't necessarily correspond to the people who are most vulnerable in the first place, right? I mean, in other words, it is not just people who had some kind of preexisting medical condition, and we are getting it. Is that right?

Ms. BACH. That is exactly correct.

Mr. RASKIN. And so what does it make you think about those who say, well, look, just let it be like, you know, low-grade flu or colds, just let it run wild, as opposed to those who are saying, no, we still have to take it seriously, get people vaccinated and get people paying attention to the public health dimensions?

Ms. BACH. From my perspective, the position that we should just let it run wild and not try to mitigate it can only be held if you do not believe that our economic security is important.

Mr. RASKIN. All right. Well, thank you very much for your work on it and for testifying, and Ms. Davis, thank you as well. And I yield back to Mr. Chairman.

Chairman CLYBURN. Thank you very much. The chair recognizes Mr. Krishnamoorthi for five minutes.

Mr. KRISHNAMOORTHI. Thank you, Chair, and thank you to all of you for coming before us. You know, in full disclosure, I should say that one of my children actually has Long COVID, and so this is an issue that I care about personally. And I wanted to just, you know, throw it out there for anybody to answer this question, which is, I guess, how much of the money that we are trying to devote to the study of Long COVID is actually going toward the study of Long COVID and children right now? And I guess, you know, what more can we do to put resources in that particular area?

Ms. DAVIS. I could take at least part of this if that is fine.

Mr. KRISHNAMOORTHI. Yes, thank you.

Ms. DAVIS. I think Long COVID in children has been dramatically understudied, in part, because all of the points I made earlier about antibody and PCR testing actually doubly applies to children. A very small percent of children test positive on PCR. There were two studies that came out showing that 50 to 90 percent of child cases are missed on PCR, even in children who then seroconvert later on. This is because children generally have lower viral loads than adults. Similarly, children also don't seroconvert nearly as often as adults, is about a third of what adults do.

And so what this ends up is these control groups where you are studying children, but you are also putting Long COVID children in the control group by accident by weeding them out with PCR and antibody tests. So I think there, again, needs to be a widespread information about PCR and antibody accuracy in children to better strengthen the research about Long COVID in children.

Mr. KRISHNAMOORTHI. Can I interrupt you? I just want to try to understand what you said. I am not so familiar with a couple of the terms that you used. Are you saying that PCR tests may not correctly predict the incidence of Long COVID or COVID in children because it doesn't register even if they have it?

Ms. DAVIS. Yes, PCR and antibody accuracy is way lower in children. Significantly, significantly lower.

Mr. KRISHNAMOORTHI. And to the point where it is usually underestimating the prevalence of COVID in children? And what are the ages that you say that where it is having that impact?

Ms. DAVIS. My understanding is it is the full age range, I believe younger than 12. It is more significantly or less accurate under 12. But the result is that you have all of these Long COVID children with negative PCRs or negative antibodies, who, in research, get put in the control the healthy control group. And so you are comparing a lot of Long COVID kids with PCR tests to a lot of healthy kids, plus a lot of Long COVID kids with negative PCR tests. And so when you compare it, it didn't look like the symptoms are that different because you are actually comparing Long COVID kids against each other.

Mr. KRISHNAMOORTHI. Oh, wow.

Ms. DAVIS. So that is a major issue I see in Long COVID research with kids. And the other thing I would bring up is that in terms of myalgic encephalomyelitis, you can have mild, moderate, and severe M.E. Severe ME is when you are bedbound, and one of the greatest risk factors for getting severe M.E. is having childhood onset, and that is not talked about anywhere. And that is one of the biggest long-term dangers I see is a lot of children who get sick for the first time as kids who keep getting repeated infections and end up bedbound to bed with, you know, all of the sensory issues that you see in severe M.E., and that makes me very worried.

Mr. KRISHNAMOORTHI. So just to recap what you said, it sounds like you are saying there are a lot of false negatives associated with PCR tests in children. I guess, let me flip the question, which is, what are some effective treatments that work better in children than adults or that are especially effective in children that perhaps people don't know about?

Ms. DAVIS. I am not sure if there are treatments that work particularly better in children, but I know that there is a very good primer on ME/CFS in children, which a lot of Long COVID in children is ME/CFS. There are researchers like Peter Rowe, who have studied this extensively, who I really believe we should be uplifting and funding because there are really, truly less than ten child experts in post-viral illness in the country. We really need them to be leading this research.

Mr. KRISHNAMOORTHI. Oh, wow. Well, thank you for that. I will just end by saying my first son, who has this Long COVID, has asthma. And, you know, when it first came on, you know, we thought it went away within, like, just a couple of days, and then months later, it came on with a roar, I mean, which is just a horrible, terrible experience. It causes the hunt for doctors all over the place to try to figure out. So I can personally attest that this is a huge problem for millions of, I mean, numerous families, and I hope that we can do more to help you to understand this. And count me, anybody else on the committee, Republican or Democrat, that is willing to team up with me on this. I would love to work with you to help our researchers here, so thank you.

Ms. DAVIS. We know that asthma and asthma and allergies are risk factors because of mast cell involvement. So you could also look for a mast cell specialist. I am sorry about your son.

Mr. KRISHNAMOORTHI. Thank you.

Chairman CLYBURN. Before recognizing Dr. Green for a closing statement, the chair recognizes Ms. Pressley. I think she has joined us.

Ms. PRESSLEY. Yes. Thank you, Mr. Chair, and thank you, Chair Clyburn, for convening today's hearing, and to the members of the Select Committee for allowing me to participate, and to the witnesses for courageously sharing your own stories and the stories of your patients, of your friends, and relatives that millions of people impacted by Long COVID.

In my district, the Massachusetts 7th, I hear similar accounts from my neighbors, like adults experiencing intense cognitive dysfunction impacting their employment and young athletes struggling to even get out of bed. Your testimony illustrates in no uncertain terms that Congress must take action to alleviate the pain, suffering, grief, and trauma resulting from the crisis within a crisis that is Long COVID. We need to advance bold, equitable policy that meets unprecedented hurt and harm with significant investments in healing and justice. Yes, our response to Long COVID should center on justice, disability justice, gender, racial, and healthcare justice.

I am grateful to the Biden Administration for taking steps to include care for those experiencing Long COVID, and our work continues, which is why I work in close partnership with Long COVID patients, advocates, clinicians, and public health experts and introduced the treat Long COVID Act to expand access to multidisciplinary treatment clinics.

Dr. Gutierrez, in your experience, how do Long COVID treatment clinics help patients?

Dr. VERDUZCO-GUTIERREZ. Thank you very much. I feel that in clinics, especially when they are multidisciplinary in nature, they was willing to take time with the patients, listen to their concerns and address, and have a good history and knowledge of other postviral illnesses and myalgic encephalomyelitis, CFS, as we have talked about today. And these are the places where patients will be able to get seen, get heard, get diagnostics that they need that are appropriate for their conditions and get individualized treatments for what they have.

Some do need resting and pacing and not traditional rehabilitation programs. Some need further workup with cardiac testing, tilt table testing to work them up for their dysautonomia. Some will need to see immunologists, rheumatologists. And so it is important that patients are working with teams, including physical medicine and rehabilitation specialists, to be able to treat their Long COVID, including, as Dr. Green talked about, the EECP, enhanced external counter-pulsation treatments.

Ms. PRESSLEY. Thank you. Ms. Davis, in your experience with Long COVID, why do you think the Federal Government should invest in multidisciplinary Long COVID clinics as an equitable patient-centered treatment option?

[No response.]

Ms. PRESSLEY. Ms. Davis?

Chairman CLYBURN. Ms. Davis?

Ms. DAVIS. Sorry. Apologies for that. I am a huge supporter of the Treat Long Covid Act. Long COVID clinics are extremely necessary to get all of the care in one place. We need clinics that don't require treatment be prioritized based on insurance coverage. We really need that clinics have access to providers who are very knowledgeable in post-viral illness, including myalgic encephalomyelitis and dysautonomia, so I really hope that we can make that happen.

Ms. PRESSLEY. And, Ms. Adinig, in just a few words, how do you think your experience to battle Long COVID would have been different? Have you had access to a clinic of informed culturally congruent specialists that could treat you and your son where you live?

Ms. ADINIG. I feel as if we had the care from the beginning, then I wouldn't be in front of you today telling the story. I would have avoided so much suffering, so much trauma to myself and my son. I would be fully recovered and doing what I do best, which is working for local nonprofits and giving back to my community.

Chairman CLYBURN. Well, thank you very much.

Ms. PRESSLEY. Is there more from Congress? How much investment is that? Thank you, Mr. Chair.

Chairman CLYBURN. Thank you, Ms. Presley. Before closing, I want to recognize Dr. Green for a closing statement.

Mr. GREEN. Thank you, Mr. Chairman, and thank our witnesses for taking time out of their day. Clearly, those of you who have had incredibly challenging experiences, thank you for sharing.

What I want to say is just because there is no accepted clinical criteria for making a diagnosis and there is not a test for the 200-plus symptoms post-COVID infection that our clinicians have identified, doesn't mean that there isn't a legit disease here or illness. It also doesn't mean that something else isn't going on. Correlation is not causation. And we as clinicians, as researchers have got to get to the bottom of it, to make assumptions because when this is happening in the chronological order of the COVID pandemic, is an informed decision, but, again, it is not research showing causation. So I want us to be careful. You should never have been dismissed. There is no clinician who should ever behave that way. And at the same time, clinicians can't just assume that something is caused by something else. We need data. And so we got to get to the bottom of it.

Which brings me to my second point that I have tried to make today is that state bureaucrats should not be telling physicians how to be physicians. Clinicians should be allowed to make clinical judgment decisions. In states like California that are trying to tell their doctors they can't do certain modalities and they can't do other things, it is just simply wrong. We train our doctors to make clinical decisions, just like this outstanding physician here who is away from her practice today, away from her patients to be here to testify. We should let them make the decisions that they have been trained to make. Thank you, Mr. Chairman, and I yield.

Chairman CLYBURN. Thank you very much, Mr. Green.

Before we close, I ask unanimous consent to enter into the record a letter the committee has received from the COVID–19 Longhauler Advocacy Project.

Without objection, so ordered.

Chairman CLYBURN. In closing, I want to thank all the witnesses who testified before us today. We appreciate your insight and expertise as we seek and learn more about Long COVID.

Now, I want to truncate my closing statement because of the vote that is on, and let me just reiterate. Vaccination is crucial in preventing severe illness, hospitalization, and death from the coronavirus. As we have heard today, it may also prevent symptoms of Long COVID. I urge all Americans who aren't currently up to date on their coronavirus vaccinations to get vaccinated and boosted as soon as possible.

With that, and without objection, all members will have five legislative days within which to submit additional written questions for the witnesses to the chair, which will be forwarded to the witnesses for their response.

Chairman CLYBURN. We are now adjourned.

[Whereupon, at 11:40 a.m., the subcommittee was adjourned.]