

Written Statement of Chimere L. Smith
Long Covid Patient Advocate for Urban Communities
Before the Subcommittee on Health
Congress of the United States
House of Representatives

Chairwoman Eshoo and Members of the Subcommittee, thank you for the opportunity to appear before you today to represent Long Covid patients — specifically black patients in urban communities. I would like to provide you an overview of my experience with Long Covid over the last year, key accomplishments of my advocacy, and the important factors we must consider as we seek to study, treat, and fight Long Covid in underserved communities.

I am not much different than many of the people who have shared their experiences living with Long Covid.

I was denied testing the first two weeks of my symptoms.

I was told over a dozen times that I never had COVID.

I tested negative for the virus and its antibodies.

The difference and challenge I face is that I am a black woman who carries the weight of other black women who have — with different but no less traumatic conditions — been left misdiagnosed, humiliated, and frightened.

Before March 2020, I can recall haphazardly listening to stories from black mothers, sisters, friends, and cousins, thinking my blue and white insurance card would absolve me from it all. From intracranial hypertension to endometriosis to cancer to arthritis to neurological diseases, these women would share with me tales of our country leaving a trail of untreated and forgotten women in hospital rooms and doctors' offices.

Over the last year, I sadly learned that even with a respectable career as a middle school English teacher, money in the bank, and a giving heart, I am still a black woman in America who doesn't know enough words to convince doctors and medical staff to take my bout with Long Covid seriously.

I have become one of the many black women I know.

Even while doing everything right, in a year, my life has become reminiscent of the little girl I tried to shed: I am once again poor, on the verge of losing my health insurance. If I didn't have a loving family, I would be living in my car — now the only possession I truly own.

Following every rule elders ever taught me about how to receive medical treatment as a black woman didn't serve me well during five horrific months without my vision as Covid caused a dense cataract to form in my left eye. Doctors shrugged it off as "dry eyes" each time I stumbled into their offices or tried to send photos of my condition. At one of the most prominent hospitals

in Baltimore, doctors refused to document my laundry list of symptoms but conferred with each other about how to convince me to enter their psychiatric ward for more evaluative mental health care.

I have spent all of my savings. I am unable to return to work. I have developed occipital neuralgia, which causes my head to feel swollen and frozen, and a misaligned spine. I am often bedbound due to fibromyalgia. My cognitive and memory functions have declined at frightening rates. As I type this, I am in awe that I am able to put these sentences together.

I have become another black disabled woman in America.

I am now a black woman with Long Covid.

I was racially profiled for complaining of a burning brain, witnessed white men receive preferential treatment while I waited for hospital staff to acknowledge me, and had to hire a patient advocate for surgeons to take my eye condition seriously.

As one would imagine, I am not eager to return to any hospital for fear of being dismissed again. However, during one of my last visits, I gained clarity on two things: I had to challenge the systemic racism I blatantly saw happening in healthcare — and now in medicine. And I would use my experience to speak to and for black, disabled women in urban communities in America with Long Covid -- millions of them I will never know or meet.

It is painfully clear that science, medicine, and research is not designed to consider the plights of black people beyond noting certain buzzwords — *underserved* and *inequities* — for notoriety.

Recently, I found encouragement in [Vice President Harris' request for urgent action in black women's maternal health issues](#). She also noted that Covid-19 has “exacerbated racial inequities in health care.” In one of the highest offices in our country, a government official has publicly acknowledged what so many of us have known for decades -- and what I had to learn in the most painful way.

It is my mission to aid government officials, researchers, and doctors in meaningful, integrous methods to include and engage black people with Long Covid in urban communities. My fear is that we've spent far too much time tracking hospitalizations and deaths, while those of us with Long Covid are suffering in silence.

[And if black women have lost jobs at a greater rate than any other race](#) over the last year, it is my hope that government and medicine act quickly as Long Covid has proven to be a crippling, disabling condition that will undoubtedly harm millions of families — especially in low-income communities, like Baltimore, which are already devastated and ravished by the effects of Covid-19.

[Last December, I was proud to contribute my experiences with Long and its impact on my community with the NIH](#). Shortly thereafter, Congress provided \$1.15 billion to the agency to study Long Covid.

I urge you to continue to impress upon the CDC and NIH that it is imperative that we create equitable research standards and practices to capture current, innovative data that focuses on black people living with Long Covid, and medical care that reflects equitable, safe, and timely education and treatment. Currently, there are no controlled studies solely focusing on the very people who have been hardest hit by Covid the most — besides American Indians and Indigenous populations. While it is impossible for me to report on any scientific data that reflects this, if my social media and email inboxes are any indication of the perils we face by not moving with urgency to study and treat black people with Long Covid, we have already reached the danger zone.

As board members of both the [Body Politic Covid-19 Support Group](#) and [Long Covid Alliance](#), I have the unique opportunity to design and support efforts to engage and educate black patients, stakeholders, doctors, and scientists who wish to study and learn about Long Covid. But this is not enough. We are in desperate need of swifter, more succinct disability policies, comprehensive educational and employment guidance that recognizes our condition, and accommodations that welcome us into research studies without conventional restrictions. Also, as there is growing evidence of the [direct connection between myalgic encephalomyelitis and Long Covid](#), we must reconcile that our unwillingness to recognize chronic conditions we can't visibly see has contributed to generations of black people who have already disappeared from society.

I often reflect on what may have happened to me had I not been angry enough to fight for my life and the lives of so many others. As a teacher in Baltimore, I learned early in my career that it was my duty to advocate for the equitable treatment of my students. There was nothing I wouldn't do to assure my "middle school babies" had the best of everything — textbooks, field trips, and social-emotional care. I wasn't afraid to speak up for them because I understood that sometimes this country does not. And I'm not afraid to speak up for them now. Losing my career has been devastating: I speak to you as an award-winning educator who planned to serve Baltimore students in an instructional leadership capacity far longer than five years. I wanted to inspire other educators to impart equitable, radical education to black students. However, what I strived for in education mirrors what I advocate for every day for black people with Long Covid.

I carry a heavy weight. I speak now so I am not just *another* disabled black woman in America carrying the sorrow, humiliation, and pain of this and other conditions on my shoulders. I speak now so my former students can access comprehensive education and treatment for Long Covid years after this is no longer a trending topic. I am now structuring a plan to use my church building and organization as a hub for black patients and their caretakers to receive Long Covid education and mental health treatment in Baltimore. Yes, I will need local, state, and federal funding. No, I don't have skills to write grants or ask for said funding. But I understand that even with a disability, in the words of [Pastor Michael Todd](#), of Transformation Church, in Tulsa Oklahoma, "all I have is all I need."

Had my voice not gotten loud enough, I may not be talking to you today. And if I can assure that the next wave of black people with Long Covid receive better treatment and care — far better than [Leiah Jones, who recently died of Long Covid](#), received — then the benefits of sharing my story as often as I can far outweigh the comforts of staying silent.

Thank you for your time and consideration.

Respectfully,

Chimère L. Smith

Patient Advocate and Consultant for Black Long Covid Patients in Urban Communities

www.chimereladawn.com

References

STAT. “In Q&A, Vice President Harris calls for urgent action on the Black maternal health crisis.” *Stat News*, 19 April 2021, <https://www.statnews.com/2021/04/19/kamala-harris-black-maternal-health-momnibus/>. Accessed 24 April 2021.

CNBC. “Black and Hispanic women aren’t sharing in the job market recovery.” 5 March 2021, <https://www.cnbc.com/2021/03/05/black-and-hispanic-women-arent-sharing-in-the-job-market-recovery.html>. Accessed 24 April 2021.

TIME. “Black Women Are Fighting to Be Recognized as Long COVID Patients.” *Time Magazine*, 12 April 2021, <https://time.com/5954132/black-women-long-covid>. Accessed 24 April 2021.

Charlotte Observer. “NC woman wrote her own obituary before dying from ‘long haul’ COVID.” *Charlotte Observer* [Charlotte], 16 April 2021, <https://www.charlotteobserver.com/news/state/north-carolina/article250690899.html>. Accessed 26 April 2021.