NYC Health

Testimony

of

**Celia Quinn, MD, MPH**
**Deputy Commissioner of Disease Control**
**New York City Department of Health and Mental Hygiene**

before the

**New York City Council**

**Committee on Women and Gender Equity**

and

**Subcommittee on COVID-19 Recovery and Resiliency**

on

# The Gendered Impact of Long COVID

September 22, 2022
Committee Room – 250 Broadway 16th Floor
New York, NY

Good afternoon, Chairs Cabán and Moya, and members of the Women & Gender Equity Committee and the Subcommittee on COVID-19 Recovery and Resiliency. I am Dr. Celia Quinn, Deputy Commissioner of Disease Control at the NYC Department of Health and Mental Hygiene. I am joined today by my colleague from Health + Hospitals, Dr. Ted Long, Senior Vice President for Ambulatory Care and Executive Director of NYC Test & Treat. Thank you for the opportunity to testify today to provide information on what is currently known about the long-term effects of COVID-19, often called Long COVID.

Scientists and clinicians are still learning about Long COVID. Generally, Long COVID refers to a wide range of new, returning, or ongoing health problems that people may experience after being infected with the virus that causes COVID-19. Although most people who have COVID-19 get better within a few days after infection, some experience prolonged symptoms. Anyone who has had a COVID-19 infection can experience Long COVID. A variety of symptoms impacting different body systems such as cognitive, respiratory, circulatory, neurological, and digestive systems, have been reported. It is likely that different pathological processes are contributing to the symptoms associated with Long COVID. Long COVID is therefore not a single disease entity or process, but likely reflects multiple ways that the virus can cause prolonged health problems in some people. There is no singular test to diagnose Long COVID, and symptoms could be caused by other health problems. For these and many other reasons, it can be difficult for people to get an accurate and timely diagnosis.

As public health experts, we want to prevent as many people as possible from getting sick. To that end, I will take a moment to speak about important preventive measures everyone can take to reduce the risk of contracting and transmitting COVID-19 and thus, dealing with potential long-term effects of the virus. It continues to be critical for New Yorkers to stay up to date with their vaccinations – including getting the new bivalent COVID-19 booster this fall. Vaccines help you avoid getting severely ill or being hospitalized. Anyone can go to NYC Vaccine Finder, to find a place to get a free vaccine close to them. I am still recommending people wear a high-quality mask in public indoor settings. Further, utilize COVID-19 testing which is now widely available. Get tested especially if you don't feel well, before and after travel or attending large gatherings; and get tested prior to visiting with someone who is at higher risk of poor health outcomes, like older adults. And if you test positive, make sure to contact your health care provider to discuss treatment options. As always, if someone does not have access to a provider, they can call 311 to get connected to care.

Like I said, staying up to date on vaccination is very important. Not only do vaccines reduce the likelihood of getting severely ill from COVID-19, but several studies have found that vaccination reduces the risk of developing Long COVID by 15-60%. It has also been found that more vaccine doses per individual may reduce the likelihood of developing Long COVID, further showcasing the importance of being up to date with booster recommendations. The Health Department is also monitoring ongoing studies that are looking to see if COVID-19 treatments, like Paxlovid, ease Long COVID symptoms—though these studies are still too new to have conclusive answers.

Currently, we have some local data on Long COVID. Data collected from the Health Department's population-based Community Health Survey conducted in 2021, suggests that up to 30% of New York adults who have had COVID-19 may experience some form of Long COVID. This survey also found that approximately 28% percent of females with a likely past COVID-19 infection reported having at least one long term physical or long term emotional or mental health issue, some had both, that they thought was due to COVID-19 compared to approximately 20% of males. We are working to enhance this survey and broaden our understanding of Long COVID by refining questions regarding symptoms, looking at the impact Long COVID has on participants' lives, and assessing their access to care. As noted above, the long-term effects of COVID-19 can manifest as a broad range of symptoms and may be due to other health problems. The survey, over time, will help us characterize Long COVID, and ensure any lessons are incorporated into public health practice. That being said, due to the many complexities to consider, it is very challenging to study Long COVID and to create surveillance systems that account for all relevant factors.

The Health Department is also reviewing studies on Long COVID including those that are looking at any differences between sexes on the impact of Long COVID, which has been reported in the news media and is the focus of this hearing. At this time, it is not yet known how much of this disparate impact is a biological difference or if it is related to various detection biases— for example, females may engage more with the health care system and/or may report the condition and symptoms more often than males. However, a UK study, found that females were more likely to have one or more persistent symptoms at 12 weeks after initial illness when compared to males. Another study published in the European Respiratory Journal, suggested that a higher prevalence of Long COVID in females could be due to higher prevalence of autoimmune diseases, for example, prevalence of Postural Tachycardia Syndrome (PTS) and Chronic Fatigue Syndrome in females, which are conditions that can be associated with Long COVID.

There is still a lot that we do not know about Long COVID, and we are still learning about the virus that causes COVID-19 itself. However, it is important that we ensure New Yorkers know about the possibility of developing Long COVID, understand the importance of avoiding COVID-19 infection in the first place, and are able to access clinical services for any symptoms that are interfering with their daily lives. On the Health Department's website, we have general information on Long COVID, as well as a non-exhaustive list of Post-COVID Care Clinics for patients experiencing continuing health issues after contracting COVID-19. Part of the intent of this list is for providers to appropriately refer patients who require specialized care. As I have mentioned, without a diagnosis—which can be difficult to obtain— getting appropriate care and support is challenging, that's why much of our educational efforts have been focused on providers. In June, the Health Department and Health + Hospitals co-hosted a Long COVID Symposium to help providers recognize possible occurrences of Long COVID amongst patients they are treating. The Health Department has also sent out communications to providers with educational resources for clinical care, information on symptoms, and patient support resources. For the public, we have run TV commercials and radio ads with Health Department doctors to increase the awareness of Long COVID symptoms. We have also been educating our Public Health Corps partners to increase community awareness and promote care-seeking for those living with Long COVID.

There is always more to do. We welcome the opportunity to hear your suggestions and questions. We rely on your partnership as you have your ear on the ground and interact with your communities daily. I am happy to have Dr. Ted Long here with me today. H+H has been at the forefront of offering comprehensive clinical services to meet the needs of patients who are navigating Long COVID, including three *COVID-19 Centers of Excellence (COEs)* and through the launch of Test & Treat's AfterCare. We are happy to answer your questions.

## Written Testimony for NYC Council Hearing on Gendered Impacts of Long COVID, 9/22 at 1pm

My name is Mae Smith and I am an Executive Director with NYC Administration for Children's Services, where I work with a team on policy reform from a racial and social justice lens to improve the safety and wellbeing of NYC's children and families.

In late March of 2020 when COVID was first spreading in the City, but before the Mayor had made the decision to close City agencies and schools, I caught Covid, likely at or going to work.

I spent two weeks feeling pretty sick, but recovering at home. I took one day off work. I was used to "pushing through" illness. City work is demanding, City agencies are understaffed, and there wasn't enough coverage when I was out. So I kept working remotely through the rest of my illness, and about two weeks later, I got better. I thought that would be it.

But then, I started feeling ill again. I went for my usual run, but this time two blocks in I was completely out of breath. Shortly after, I was running a fever. Something wasn't right.

I called NYC's COVID hotline. They told me, straight up – that's not possible. You can't get COVID twice. It's probably a cold or flu. Just rest.

Then, over the course of the next several months, my health descended rapidly. After even the smallest physical exertion, my body and mind were completely wrecked. If I was in a Zoom meeting for more than 20 min, I couldn't focus anymore - my brain just stopped working. I couldn't think clearly, I couldn't exercise, I could hardly walk up stairs. If I tried to push myself even a little bit, I wound up in bed for days with a migraine, fever and complete exhaustion. My body was completely different; I didn't recognize the body I was living in anymore.

I knew this wasn't normal fatigue or stress. For my entire adult life, I had held multiple jobs at a time, volunteered, had a regular fitness routine and an active social calendar. Now, after preparing a simple meal or taking a shower, I needed to rest in a dark room.

It was the last thing I wanted to do, but I knew I wasn't well enough to work anymore. I told my boss I'd need to take a month off while I figured out what was wrong. One month turned into two, three, five, and finally eight.

Then I found the Body Politic Long COVID support group. I learned that what I was going through wasn't new at all, but in fact had happened to countless others following viral infections who had been struggling to get recognition and treatment for *decades*, and was now happening, in massive numbers, to people who had had COVID.

I also started getting phone calls from colleagues and loved ones - all going through the same thing. *"I had COVID and I thought I got better, but now I am just so tired, I can't think straight, I have constant headaches, my heart beats uncontrollably fast."*

I went to many other doctors, but none knew what was wrong or how to treat me. The worst ones said my tests looked normal, so it must be all in my head. The good ones said I believe you, I've seen many other patients who are experiencing the same thing after COVID, but I'm so sorry, I don't know what's wrong or how to make it better.

I passed my days on the phone between doctors and insurance, spending precious energy I didn't have, followed by hours or even days to recover. Desperately trying to get decent care had become a full-time job, unpaid and agonizing.

Then, through the patient support group, I learned that there was ONE physician in the greater New York area who specialized in me/cfs and other post-viral illnesses. ONE. Dr. Susan Levine. I called her and was lucky to get in. I believe she now has a waitlist nearly a year long, so most other Long COVID patients are not so fortunate.

Having treated post-viral illness for decades, she knew what to look for. She ran comprehensive blood tests that other doctors never knew to. She quickly put me on medications for reactivated EBV, sent me to a cardiologist who specializes in dysautonomia, a neurologist who specializes in neuropathy, and put me on medications to help with neuro-inflammation and blood clotting, all things very common in Long COVID patients but which most still don't have access to treatment for.

I slowly, slowly got better over the course of the next year and a half. I am still nowhere near my pre-COVID self. My heart rate skyrockets when I'm upright. I still get headaches and extreme fatigue if I do too much activity, physical or mental, so I need to carefully pace myself and limit what I do.

I'm not cured, but I'm also one of the *lucky* ones. Most Long COVID patients are still unable to access doctors who can help them at all.

I was also extremely fortunate to be able to return to work, with a Reasonable Accommodation to continue working remotely at a reduced schedule, something most of my fellow City workers with Long COVID don't have access to.

I tried to sound the alarm at the City agency I work for.

If the City removes remote options and forces all its' workers back into offices while COVID was still rampant –
If the City removes mask mandates in City offices, and later in public transportation –
If the City doesn't provide sick leave and accommodations its' workers –
If the City doesn't make rapid progress on providing education, treatment, and supports to New Yorkers suffering from Long COVID –

*It's out of our control*, was always the response. *It's up to the Mayor*. And Mayor Adams wanted people back in offices. Protecting City workers and New Yorkers didn't factor into his plan at all.

So, here we are. More and more New Yorkers are becoming disabled every day – unable to work, unable to care for their children and loved ones. My heart breaks watching colleagues and loved ones become sick and disabled from COVID, oblivious to the fact that even a mild case could change their lives forever, because the City has failed to act.

This is the first hearing the Council has held on Long COVID.

I want to thank Council Member Tiffany Caban, and the Committee on Women and Gender Equity and Subcommittee on COVID Recovery and Resilience, from the bottom of my heart for giving this critical issue the attention and urgency it requires.

And I want to implore the full City Council, the Subcommittee on COVID Recovery and Resilience, DOHMH, H+H and the Mayor's office — don't let this be the last.

If you care about this City and it's people, our health, our workforce, our economy — you must act swiftly and collectively to dedicate the City resources required to reverse the course of this mass disabling event that is barrelling forward.

Our future quite literally depends on it.

## Oral Testimony for NYC Council Hearing on Gendered Impacts of Long COVID, 9/22 at 1pm

I'm submitting a more detailed version of this testimony in written form, but today I want to tell you just a bit about my experience.

Several months after my initial "mild" case of COVID in April 2020, my health descended rapidly. After even the smallest physical exertion, my body and mind were completely wrecked. If I was in a Zoom meeting for more than 20 min, I couldn't focus anymore - my brain just stopped working. I couldn't think clearly, I couldn't exercise, I could hardly walk up stairs. If I tried to push myself even a little bit, I wound up in bed for days with a migraine, fever and complete exhaustion. My body was completely different; I didn't recognize the body I was living in anymore.

I knew this wasn't normal fatigue or stress. For my entire adult life, I had held multiple jobs at a time, volunteered, had a regular fitness routine and an active social calendar. Now, after preparing a simple meal or taking a shower, I needed to rest in a dark room.

It was the last thing I wanted to do, but I knew I wasn't well enough to work anymore. I told my boss I'd need to take a month off while I figured out what was wrong. One month turned into two, three, five, and finally eight.

I passed my days on the phone between doctors and insurance, spending precious energy I didn't have, followed by hours or even days to recover. Desperately trying to get decent care had become a full-time job, unpaid and agonizing.

Then, through the patient support group, I learned that there was ONE physician in the greater New York area who specialized in me/cfs and other post-viral illnesses. ONE. Dr. Susan Levine. I called her and was lucky to get in. I believe she now has a waitlist nearly a year long, so most other Long COVID patients are not so fortunate.

Having treated post-viral illness for decades, she knew what to look for. She ran comprehensive blood tests that other doctors never knew to. She quickly put me on medications for reactivated EBV, sent me to a cardiologist who specializes in dysautonomia, a neurologist who specializes in neuropathy, and put me on medications to help with neuro-inflammation and blood clotting, all things very common in Long COVID patients but which most still don't have access to treatment for.

I slowly, slowly got better over the course of the next year and a half. I am still nowhere near my pre-COVID self. My heart rate skyrockets when I'm upright. I still get headaches and extreme fatigue if I do too much activity, physical or mental, so I need to carefully pace myself and limit what I do.

I tried to sound the alarm at the City agency I work for, warning what would happen if we continued dismantling public health protections. *It's out of our control*, was always the response. *It's up to the Mayor*. And Mayor Adams wanted people back in offices. Protecting City workers and New Yorkers didn't factor into his plan at all.

It still doesn't.

CALLEN-LORDE

# TESTIMONY BEFORE THE NEW YORK CITY COUNCIL
## Committee on Women & Gender Equity and Subcommittee on COVID Recovery and Resiliency

**September 22, 2022**

Submitted by
**Elsbet Servay, FNP-BC, AAHIVS**
**Immunization Clinical Director**

Delivered (Orally) by
**Kimberleigh Joy Smith, MPA**
**Senior Director of Public Policy and Advocacy**

Good Afternoon. Thank you, Chairs Cabán and Moya for the opportunity to testify this afternoon. My name is Kimberleigh Joy Smith, and I am the Senior Director of Public Policy and Advocacy for Callen-Lorde Community Health Center, which provides services focused on New York City's lesbian, gay, bisexual, and transgender communities while remaining welcoming to all, regardless of ability to pay. The health center serves as an affirming environment for patients seeking culturally competent care, who come from over 195 zip codes across the five boroughs of New York City.

I am here this afternoon delivering testimony on behalf of my colleague Elsbet Servay, a Family Nurse Practitioner who has worked at Callen-Lorde for five years and worked in healthcare for 13 years.

All New Yorkers have felt the impact of COVID-19 on their lives over the past two and a half years. Many are still struggling with long-term effects of the disease, known as “long COVID” or Post-acute Sequelae of SARS-CoV-2 infection (PASC). PASC has highly variable clinical presentation; often goes unrecognized both by those suffering from it and underdiagnosed by the healthcare system at large; and as of yet, has no single clearly identified treatment. PASC is defined by the CDC as “wide range of health consequences that are present four or more weeks after infection with SARS-CoV-2,[1].” COVID-19 disease affects a wide array of organ systems, including the respiratory, cardiovascular, nervous, gastrointestinal, musculoskeletal, renal, and dermatologic systems. Data from the National Center for Health Statistics (NCHS) Household Pulse Survey indicates that 1 in 5 Americans experience PASC symptoms and that women, transgender persons, bisexual individuals, and Hispanic adults are more likely to report PASC than other groups[2]. This translates to hundreds of thousands of New Yorkers suffering from the condition.

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[1] https://www.cdc.gov/coronavirus/2019-ncov/hcp/clinical-care/post-covid-conditions.html
[2] https://www.cdc.gov/nchs/pressroom/nchs_press_releases/2022/20220622.htm

CALLEN-LORDE

In my experience as a primary care provider at Callen-Lorde Community Health Center, a Federally Qualified Health Center whose mission is to serve New York's lesbian, gay, bisexual, and transgender communities, I have seen then negative impact of COVID-19 and PASC on many of the most vulnerable members of society first-hand. Some of my patients were not even aware that they were entitled to paid sick leave throughout the pandemic, and I had to educate them on NYC law. Several of those diagnosed with PASC have dropped out of the workforce due to ongoing health concerns. Many were unaware of the option to apply for disability before leaving the workforce, which complicated their application process for benefits later on. Even for the patients who were savvy enough to apply for disability, the documentation requirements are cumbersome and time-intensive for patients and providers alike. Referrals to specialty PASC clinics often involve lengthy wait times and treatment options are often limited. For those with symptoms that are hard to quantify, such as psychiatric symptoms, chronic fatigue and "brain fog", claims are likely to be denied and questioned extensively by insurers. Insurers have also denied claims for PASC disability based on the lack of documentation of a positive COVID-19 test—an issue when many rely on at-home rapid testing.

Staffing shortages at our clinic have also made it harder to process claims within the narrow timeframes available. Case managers with detailed knowledge of navigating the complexities of benefit programs have been working at reduced capacity and are often only available remotely. This makes it harder for patients with limited bureaucratic literacy to get support with form completion, and I often must support my patients with this process instead (this includes telling them where to write their names and sign forms). The 17 minutes I am allotted for primary care visits is insufficient for this and time spent on form completion could often be better utilized educating them on symptom management.

I believe that an educational outreach campaign on the symptoms of PASC, the availability of paid sick leave, and the process for applying for disability, either through employer or the state, would have a great impact on many New Yorkers suffering from this condition. Targeted outreach campaigns designed to reach those with nontraditional employment, low literacy, non-English speakers, women, and sexual and gender identity minority patients would help those most disenfranchised and least likely to be aware of the options available to them. Programs that offer support in applying for disability for those affected by COVID-19 and PASC would have a significant impact. Expanding disability or offering provisions for supporting those who, due to illness, require support with unpaid work like caregiving and parenting would also be useful in creating a more just NYC.

Thank you again for this opportunity. We will submit our written comments for the record.

**For more information, please contact Kimberleigh J. Smith at Ksmith@Callen-Lorde.org.**

Good afternoon City Council members,

Thank you for your time and efforts today regarding this very important matter that impacts tens of thousands of New Yorkers. I am speaking to you today as a Long COVID clinician, researcher, and also a family member of someone severely impacted by Long COVID and remains on medical disability- who was diagnosed with Long COVID more than a year after I started my clinical and research work.

I am an assistant professor of medicine and infectious diseases specialist at Columbia University Medical Center, where I lead efforts in the division of infectious diseases regarding long COVID. I have also participated as a panelist in the NY state and NYC symposiums on Long COVID as a clinical and research expert. My professional experience with post-viral syndrome far pre-dates COVID and started during my time working with Ebola survivors in West Africa in Liberia as an epidemiologist at the CDC. I saw first had the impact of post-Ebola syndrome, which is strikingly similar to long COVID in many ways.

When COVID hit New York in March of 2020, I replicated the viral persistence and post-Ebola syndrome work I did in West Africa to create a longitudinal research study at Columbia. We detected signals in our data by the summer of 2020 of neurologic long covid and we have expanded our efforts to include more comprehensive and target surveys for long COVID specific symptoms and are collaborating with several labs across the country to perform advanced laboratory testing to help identify what exactly is causing Long COVID. To date, we have recruited over 500 participants and more than half are endorsing long term symptoms. Our collaborators range from labs at Columbia, other academic centers across the nation, private biotechnology and pharmaceutical companies, and the New York City Department of Health.

In addition to my research efforts, I personally provide clinical care to more than 50 patients with severe symptoms- working with various sub-specialists across Columbia. My patients present with a variety of types of Long COVID, ranging from chronic fatigue syndrome, brain fog, dysautonomia/POTS, mast cell activation syndrome, irritable bowel syndrome, ringing in the ear, peripheral neuropathy, as well as pulmonary and cardiac long COVID. Unfortunately, many of my patients have had to take time off of work and I frequently assist with writing letters of medical necessity for unemployment and disability claims.

I kindly ask the council to continue to listen to the voices of Long COVID patients, advocates, clinicians, and researchers, as Long COVID is clearly a public health concern that requires assistance with resources and city-level efforts to provide better care to New Yorkers. Thank you.

Dr. Lawrence Purpura

# Main Points

Post-COVID illnesses are likely to be a very large financial burden to society and to governments

The condition called “Long COVID” has been found to have multiple underlying abnormalities in the body

A considerable research effort is underway at NIH and CDC to understand these abnormalities and to find effective treatments

# Post-COVID Illnesses

- Increased rates of several major illnesses: in the year following COVID rates of heart attacks, lung failure, diabetes and early death increase 150-400%

- New kinds of diseases caused by injury to the lungs, heart, kidneys, and brain

- “Long COVID”—a lingering illness: fatigue, brain fog, aching muscles, disrupted sleep, symptoms worsened by physical or mental exertion

# Projected Economic Impact

**Four primary sources:**

- ***Brookings Institution Report, 8/22 (K Bach):*** ***https://www.brookings.edu/research/new-data-shows-long-covid-is-keeping-as-many-as-4-million-people-out-of-work/***
- ***CDC/NCHS Household Pulse Survey on Prevalence of Post-COVID (6/22)*** ***https://www.census.gov/data/experimental-data-products/household-pulse-survey.html***
- ***National Bureau of Economic Research, 9/22***
- ***Analysis by David Cutler and Lawrence Summers, 8/22***

# Economic Impact of Post-COVID Illness

## *Brookings/Nat. Ctr. Health Statistics*

- **16 million adults in U.S. have post-COVID illness, and 2-4 million are out of work because of it – 1.8% of the total civilian labor force**
- **The *annual* cost of foregone wages in this group: $170-230 billion**
- **Plus *annual* cost of medical care and other factors: $544 billion[Cutler, Summers]**
- **Aggregate cost to U.S. over 5 years: $3.7T, same impact the Great Recession[Cutler, Summers]**

# Who Gets Long COVID?

- **Somewhat more likely to occur in the people who were sickest when they first got COVID.**
- **However… it can occur even in people with the mildest initial COVID illness**
- **Risk greater in women, older adults, people with chronic illnesses, people in underserved communities**

***Ayoubkhani D, et al. June 4, 2021. Office for National Statistics, U.K.***

# Underlying Bodily Injuries Post-COVID

**Abnormalities of the:**

***Brain:*** **Autonomic system and brainstem, small nerves (neuropathy), brain inflammation, death of brain cells & reduced brain size (gray matter and white matter)**

***Immune system:*** **Autoimmune (autoantibodies), immune cell activation & exhaustion**

***Cardiovascular:*** **Blood vessel abnormalities (more likely to form clots and go into spasm), reduced exercise capacity**

***Energy metabolism:*** **Cells less able to make and use energy**

# What’s Being Done To Reduce Burden?

- Research to better understand what is going wrong in the body (NIH): biomarkers, targets for new drugs
- Research on prevention, primarily more durable vaccines (1 shot or nasal spray)
- Trials of already-available drugs and experimental drugs

NIH budget: $1.15 billion

# Beyond Research: Other Support Measures

- **Expanded health insurance**
- **Expanded paid sick leave**
- **Increased access to SSDI: biomarker, eliminate 12-month rule**
- **Encourage more workforce accommodations for those partially disabled: work by disabled people *rose* 13% during pandemic, largely remote work**

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I am pleased to have been involved in the care of Chronic Fatigue Syndrome (ME/CFS) patients for over three decades of my career, and now, as a natural extension of my familiarity with this disease have begun evaluating Long Hauler patients.

I completed fellowships in Infectious Diseases and Allergy and Immunology in the late 80's and afterwards began seeing patients in private practice. Thereafter, I became involved in some clinical studies that helped build the case definitions that we use, such as the Canadian case definition for ME/CFS which lays out the necessary clinical criteria to make this diagnosis.

Ove the years it became clear that there were certain `co morbid' disorders that accompanied ME/CFS including orthostatic intolerance; mast cell activation syndrome; gastric dysmotility and Fibromyalgia. Neuropathy and disorders for the spine, i.e. cranio cervical instability are also being recognized as other disease that are common among ME/CFS

ME/CFS patients have been marginalized for many decades and they have suffered for it. Just now some primary care physicians, mainly at medical centers or in urban areas are learning to recognize this complex disorder but few have learned to treat it. Recognizing and acknowledging the suffering of patients afflicted with ME/CFS, an invisible illness, is so critical to moving forward with treatment.

There are far too few doctors who not only can recognize the cardinal symptoms of this disease but too few specialists, such as cardiologists, who can diagnose the orthostatic related problems; the gastroenterological complications and the neurological sequelae of this illness.

My hope is that with the advent of Long Covid and untold sequelae of this devastating viral illness that doctors, other health care professional, family, employers and disability companies, including the Federal Government can recognize the devastating effects of this illness which in so many ways resembles the natural history of ME/CFS.

Not only do we need more health care professional taking care of patients `in the trenches' but we need vast federal funding (and private donors) to support the much needed research this disease craves.

It is clear from the results of mine and my collaborators' research at Columbia's Mailman School of Public Health, led by Drs. Lipkin and Hornig, in addition to other clinical collaborators across the country that there are a myriad of immune, metabolomic, proteomic and microbiome abnormalities in ME/CFS patients. We can capitalize on these findings to develop new treatments and fast track them instead of waiting years for the FDA to approve them.

Other strategies for helping to treat ME/CFS and Long Haul Covid sufferers include trying low risk interventions, including medications, supplements, other treatment modalities, including acunpuncture and some supplements with mitochondrial enhancing effects that would be considered `off label'. For instance, several ongoing studies in Long Haul Covid feature the use of metformin and atorvastatin, glucose lowering and lipid reducing drugs, respectively for their anti inflammatory benefits.

It is time that we stood up for ME/CFS patients and for Long Haulers as their needs have been ignored for far too long!

Susan Levine, MD

**Written Testimony from Dr. David Putrino, Mount Sinai for “The Gendered Impacts of Long COVID” Hearing on 9/22 at 1pm**

My name is Dr. David Putrino, PhD and I am the director of rehabilitation innovation for the Mt. Sinai Health System.

**Past**

We identified Long COVID in May of 2020 when we noticed that roughly 15% of the thousands of acute COVID patients were developing chronic symptoms.

As we started managing the care of people with Long COVID, we began to publish findings describing common presentations and symptom severity associated with Long COVID:

- Up to 70% female with significant symptoms worsening in the pre-menstrual period. This is a condition that disproportionately disables women.
- 50% of our patients had experienced a change in employment status due to their Long COVID symptoms. 30% of this 50% are now unemployed.
- Over 60% of our patients were experiencing measurable cognitive impairment.

**Current**

Many Long COVID clinics are still turning patients away if they don’t have a positive PCR or AB test. This is against CDC policy and diagnostic criteria. <u>We need policy to enforce CDC policy that everyone who meets diagnostic criteria can be seen by a Long COVID clinic</u>. Otherwise this will significantly worsen existing disparities in care.

<u>We also need free clinics with Long COVID expertise</u>. I am willing to educate physicians who do not already have this experience or expertise.

Similarly, many insurers are denying claims for necessary care. The argument is that “necessary care” is poorly defined in Long COVID, so we are in a dangerous scenario where insurers get to determine what “necessary care” entails. <u>We should be developing policy to guide and enforce standards for necessary care.</u>

Many short- and long-term disability claims are being denied due to insufficient evidence of disability. <u>Clinicians should be educated to use validated instruments to measure disability so that they can make a better case for patients</u>.

**Future**

Dr. Akiko Iwasaki and I recently released a pre-print showing that we can identify people with Long COVID from a control group using blood biomarkers with 96% accuracy. However, these blood tests are inaccessible to most Medical Doctors and certainly not covered by insurance. <u>We would like to work with the government to create a Rapid Biotech Translation pipeline.</u> This is a public health crisis and a mass disabling event that worsens every day. We need rapid action and we have the tools to make a difference.

We need protections in place for vulnerable populations. We needed them yesterday. I can’t say plainly enough that current public health policy surrounding masking, ventilation and infection-prevention is not consistent with the available science. If we aren’t going to follow the science, we must at least protect vulnerable populations from further harm.

September 22, 2022

# Testimony to the NYC City Council Hearing on Gendered Aspects of Long COVID

**JD Davids, Brooklyn NY**

**Co-founder, Network for Long COVID Justice / Strategies for High Impact**

As a transgender person living with Long COVID, I will focus my remarks on the pressing need for Long COVID information, care, treatment and support for transgender people, who are among the most affected by Long COVID as well as those most marginalized from economic stability and access to care and public programs.

When I say transgender or trans, I am speaking of people who may identify as transgender, non-binary or gender non conforming.

I wish to give particular emphasis on the need to center Black, brown and indigenous trans people who often face the highest rates of discrimination, bias and health challenges. I also recognize the powerful and life-affirming networks of trans people in our own communities, including those in Black and Brown communities anchored by transgender women, femmes and non-binary people.

Rather than consigning us to a “you do you” individualistic rat race where trans people often lose, or giving resources to primarily LGB groups that lack accountability to trans people, I urge you to recognize that “we do us,” and resource trans people and our groups for the work we have always done to care for one another.

Long COVID is a trans issue. This year, what we long suspected was confirmed in the U.S. Household Pulse study. As summarized by LGBTQ media outlet Them:

> In addition to showing higher rates of long COVID in younger adult populations and women, the Census Bureau survey also revealed that trans and bisexual adults are much more likely to report having the

disease. Compared to 5% of cisgender men and 9% of cisgender women, 15% of trans adults in the U.S. say they are currently experiencing long COVID symptoms. Meanwhile, 12% of bisexual adults in the U.S. are living with post-COVID conditions, compared to 7% of straight, gay, and lesbian adults. Those rates mirror broader health disparities experienced by the trans and bisexual communities — and point to disconcerting ways our healthcare systems may be failing them.

Transgender people, including transgender undocumented immigrants and transgender sex workers,whose lives are explicitly criminalized, experience high rates of systemic bias and violence, including in healthcare settings.

Transgender people -- especially Black, brown and indigenous trans people -- are also likely to have comorbidities that can increase risk of both COVID-19 harms as well as Long COVID.

For example, in a 2019-2020 study on HIV Prevalence Among Transgender Women in 7 US Cities, 42% of women interviewed were living with HIV -- including 62% of Black/African American women, 35% of Latina women and 17% of white women.

Recent research from Drs. Deeks at the University of California San Francisco validates trends seen in early studies: People living with HIV are four times as likely to have Long COVID than those who are HIV negative.

The complexities faced by trans people in accessing medical care are compounded by living with complex chronic conditions like Long COVID, or myalgic encephalomyelitis, or ME, which may affect 50% of people with Long COVID. Our health needs in this crisis require specific and sustained support.

With limited time, I will now move to four recommendations for addressing this crisis.

1) **Prioritize diagnosis and treatment of Long COVID in LGBTQ health settings,** including in the H+H Pride Centers, Callen-Lorde Health Center, and others, as well as clinics and medical settings giving care for transgender people who are living with HIV, who are sex workers, who are

imprisoned or in congregate living settings.

2) **Ensure that all settings giving Long COVID care have training and support to give gender-competent car**e, such as the H+H Centers of Excellence, hospital-based Long COVID Clinics, and others. This should include provision of gender-confirming hormones and referrals for surgical care, without requiring trans people with Long COVID to go to a separate site for basic gender-related care that is within the capacity of trained primary care providers. Years of experience in HIV care shows us that integration of gender care is essential to making chronic illness care work for trans people.

   This must include not just medical training for providers, but comprehensive training and accountability to all who we encounter in care settings, including front desk staff, call center staff and others, to ensure we are not misgendered or experiencing bias. Microaggressions have health consequences of their own, and also add further discouragement when we face confusing, complex conditions that are threatening our very lives. We need welcoming, competent and warm environments that give us the compassionate care we need at every level, from each person we encounter.

3) **Train and employ trans people as Long COVID-focused community health workers, doulas and home health aides to education, support and care for trans people and others with Long COVID in New York City.** Many trans people, including immigrants and sex workers, were left out of the stimulus or locked out of state excluded worker funds that did not reach enough of those in need. Trans people also often lack a network of family support that can sustain others in a crisis, and may face a lack of understanding or outright bias from non-trans support systems.

Thank you.

JD Davids

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**From:** Tatiana Bejar <tatiana@domesticemployers.org>
**Sent:** Friday, September 16, 2022 9:00 AM
**To:** Testimony
**Subject:** [EXTERNAL] Hearing at Committee on Women and Gender Equity on 9/22

Good morning,

My name is Tatiana Bejar and I'm the coordinator of the NYC Coalition for Domestic Work. We are interested in testifying at the hearing on 9/22. Can we register through this email?

We are interested In having a panel for our coalition composed of domestic workers and employers who are members of our organizations: National Domestic Workers Alliance, Hand in Hand: The Domestic Employers Network, Adhikaar, and Carroll Gardens Association. I also would like to confirm if there would be interpretation available to Spanish and Nepali.

Thank you for all your support!
Tatiana

Tatiana Bejar
New York City Lead Organizer
Hand in Hand: The Domestic Employers Network
NYC Coalition for Domestic Work
tatiana@domesticemployers.org | 917-597-6941
Pronouns: she/her
Visit our website at domesticemployers.org
Follow us on twitter @HiHemployers
Instagram @hihdomesticemployers
Like us on facebook

Join Hand in Hand today! Contribute to Hand in Hand and become a member of a vibrant national network of domestic employers, caregivers, and allies who are building a more just, equitable and caring society.

Therese Russo
Testimony for NYC Council Hearing on
“The Gendered Impact of Long COVID”
September 22, 2022

My name is Therese Russo and I am a Long COVID advocate with the National Network for Long COVID Justice - NY, and the New York state chapter leader for #MEAction, a global network of advocates that fight for health equity for people living with myalgic encephalomyelitis/chronic fatigue syndrome (ME/CFS) and other disabling, complex chronic diseases. My career background is in public administration, and health policy and advocacy. I am chronically ill and have been disabled with ME/CFS and postural orthostatic tachycardia syndrome (POTS) for nearly 5 years.

Core symptoms in my daily experience of ME/CFS, which started after a flu-like illness I got in my early 20s, include: extreme, unexplained persistent fatigue that is not substantially alleviated by rest and has lasted years; disrupted and unrefreshing sleep; post-exertional malaise, or an exacerbation of symptoms following exertion; brain fog and other cognitive dysfunction; and chronic migraines and sensory sensitivity.

Long COVID has been defined as a collection of symptoms that develop during or after a confirmed or expected case of COVID-19, and last for more than 28 days.[1] Some of the most frequent symptoms found in Long COVID that lasts for longer than 6 months are: fatigue that is substantial enough to disrupt daily function; post-exertional malaise; and cognitive dysfunction.[2] Later in this testimony I speak more to the overlap between ME/CFS and Long COVID.

I am here to testify that there is a 2nd pandemic happening on New York City’s watch - a pandemic of chronic disease and disability that is following in the wake of infection and reinfection from SARS-CoV-2. **As council member Caban stated, we are in the middle of a mass disabling event. We need New York City and its public health, healthcare, and social service institutions to respond boldly and urgently to this crisis.**

The CDC estimates that as many as 24 million people are living with Long COVID in the U.S. Women, transgender adults, bisexual adults, and hispanic people are more likely

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[1] CDC (2022 September 1). Long COVID or Post-COVID Conditions. https://www.cdc.gov/coronavirus/2019-ncov/long-term-effects/index.html
[2] Davis, H. E., Assaf, G. S., McCorkell, L., Wei, H., Low, R. J., Re'em, Y., ... & Akrami, A. (2021). Characterizing long COVID in an international cohort: 7 months of symptoms and their impact. EClinicalMedicine, 38, 101019.

to experience it than other groups[3]. Children also get Long COVID.[4] A recent Brookings study reports that up to 4 million working age Americans are completely out of work due to Long COVID and that the economic burden in lost wages is approaching $200 billion a year and likely to rise.[5] In NYC, unpublished survey data suggest that up to 30% of people who are infected with SARS-CoV-2 develop Long COVID symptoms.

Long COVID encompasses multiple symptoms and conditions that follow infection, but the group my advocacy efforts focus on are those experiencing debilitating symptoms for months and years after infection, and who are developing conditions like the one I have had for 14 years - ME/CFS. ME/CFS is a disabling, chronic neuroimmune condition that often follows a viral infection.[6] 75% of people with it are unable to work, and 25% are homebound or bedridden. Only 5% recover. Its hallmark is post-exertional malaise (PEM), an exacerbation of some or all of an individual's symptoms that occurs after physical or cognitive exertion and leads to a reduction in functional ability.[7] Multiple studies have reported that people with ME/CFS are more functionally impaired and have poorer quality of life than those with multiple sclerosis, congestive heart failure, stroke, and end-stage renal disease.[8] ME/CFS is often comorbid with autonomic nervous system dysfunction (dysautonomia), namely orthostatic intolerance, another poorly understood set of disorders having to do with blood circulation dysfunction, and

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[3] National Center for Health Statistics. Post-COVID Conditions. Available from: https://data.cdc.gov/d/gsea-w83j.

[4] Lopez-Leon, S., Wegman-Ostrosky, T., Ayuzo del Valle, N.C. et al. Long-COVID in children and adolescents: a systematic review and meta-analyses. Sci Rep 12, 9950 (2022). https://doi.org/10.1038/s41598-022-13495-5

[5] Bach, K. (2022, August 24). *New data shows long Covid is keeping as many as 4 million people out of work.* Brookings Institution. https://www.brookings.edu/research/new-data-shows-long-covid-is-keeping-as-many-as-4-million-people-out-of-work/

[6] CDC. *What is ME/CFS*. https://www.cdc.gov/me-cfs/about/index.html

[7] Committee on the Diagnostic Criteria for Myalgic Encephalomyelitis/Chronic Fatigue Syndrome, Board on the Health of Select Populations, & Institute of Medicine. (2015). Beyond Myalgic Encephalomyelitis/Chronic Fatigue Syndrome: Redefining an Illness. National Academies Press (US); Carruthers BM, Jain AK, De Meirleir KL, Peterson DL, Klimas NG, Lemer AM, Bested AC, Flor-Henry P, Joshi P, Powles ACP, Sherkey JA, van de Sande MI. Myalgic encephalomyelitis/chronic fatigue syndrome: Clinical working case definition, diagnostic and treatment protocols (Canadian case definition). Journal of Chronic Fatigue Syndrome. 2003;11(1):7–115.

[8] Falk Hvidberg, M., Brinth, L. S., Olesen, A. V., Petersen, K. D., & Ehlers, L. (2015). The Health-Related Quality of Life for Patients with Myalgic Encephalomyelitis / Chronic Fatigue Syndrome (ME/CFS). PloS one, 10(7), e0132421. https://doi.org/10.1371/journal.pone.0132421; Twisk FN. The status of and future research into myalgic encephalomyelitis and chronic fatigue syndrome: The need of accurate diagnosis, objective assessment, and acknowledging biological and clinical subgroups. Frontiers in Physiology. 2014;5:109.

characterized by the inability of the body to correctly regulate blood pressure, cerebral blood flow and consciousness when in an upright position.[9] [10]

Multiple recent studies report that nearly half of people with Long COVID meet the diagnostic criteria for ME/CFS, and that over half of them experience moderate to severe autonomic dysfunction.[11] So if the CDC estimates that as many as 24 million people are living with Long COVID in the U.S., then up to about 12 million of those people likely meet the criteria for ME/CFS and/or dysautonomia.

Experts and advocates in infection-associated chronic diseases saw this tsunami of new onset chronic illness coming,[12] and from March 2020, they have been working to educate, care for, and study people who aren't recovering after SARS-CoV-2 infection. But the number of people and other resources engaged in these efforts do not nearly meet the scale of the need. A coordinated, whole-of government approach is required to address this complex problem.

#MEAction's federal agency advocacy team, the Patient-Led Research Collaborative, the COVID-19 Longhaulers Advocacy Project, and other patient-led advocacy groups, individuals, and experts involved in the Long Covid Alliance[13] have been urging, as well as collaborating with, the NIH, CDC, HHS, and other federal agencies to do more to track, understand, care for, and support the millions of people experiencing the long-term impacts from SARS-CoV-2. In addition to carrying out their own internal projects and nurturing networks of community support, these advocacy groups have helped shape and/or provided input to the NIH RECOVER Initiative; the creation of an ICD-10 code for post-COVID conditions; the qualification of Long COVID as a disability

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[9] Benarroch EE. Postural tachycardia syndrome: A heterogeneous and multifactorial disorder. Mayo Clinic Proceedings. 2012;87(12):1214–1225; Okamoto LE, Raj SR, Biaggioni I. Chronic fatigue syndrome and the autonomic nervous system. Primer on the Autonomic Nervous System. 3rd. Robertson D, Biaggioni I, Burnstock G, Low PA, Paton JFR, editors. Oxford: Academic Press; 2012a. pp. 531–534.

[10] Stewart, Julian M; Medow, Marvin S (February 2, 2015), "Orthostatic Intolerance", Medscape.

[11] Mancini DM, Brunjes DL, Lala A, Trivieri MG, Contreras JP, Natelson BH. Use of Cardiopulmonary Stress Testing for Patients With Unexplained Dyspnea Post-Coronavirus Disease. JACC Heart Fail. 2021 Dec;9(12):927-937. doi: 10.1016/j.jchf.2021.10.002; Kedor, C., Freitag, H., Meyer-Arndt, L. et al. A prospective observational study of post-COVID-19 chronic fatigue syndrome following the first pandemic wave in Germany and biomarkers associated with symptom severity. Nat Commun 13, 5104 (2022). https://doi.org/10.1038/s41467-022-32507-6; Haffke, M., Freitag, H., Rudolf, G. et al. Endothelial dysfunction and altered endothelial biomarkers in patients with post-COVID-19 syndrome and chronic fatigue syndrome (ME/CFS). J Transl Med 20, 138 (2022). https://doi.org/10.1186/s12967-022-03346-2; Larsen et al., Characterization of Autonomic Symptom Burden in Long Covid. medRxiv 2022.04.25.22274300; doi: https://doi.org/10.1101/2022.04.25.22274300

[12] Hornig, M. (2020 April 17). What does COVID-19 portend for ME/CFS? New York, NY: Columbia University Mailman School of Public Health. https://solvecfs.org/wp-content/uploads/2020/04/COVID19-MECFS_Sci_Review.pdf

[13] The Long COVID Alliance was co-founded by Solve M.E., the Global Pandemic Coalition and the COVID-19 Longhaulers Advocacy Project in Spring 2020.

under the Americans with Disabilities Act (ADA); the CDC's Long COVID and Fatiguing Illnesses Recovery Program; and the appointment of a Long COVID coordinator at the HHS, which at President Biden's direction recently released two reports that inventory current Long COVID services and outline a national research action plan. These reports signal promise, but they come without funding or implementation plans.

New York City is a leader in the state, nation, and world. Where is its Long COVID action plan? Why has its government not appointed a Long COVID coordinator? Why is the DOHMH not tracking Long COVID cases and reporting those metrics on its COVID dashboard? Given the silent epidemic of chronic disease in our city now, is the city improving worker accommodations, including for domestic and gig workers? Is it seeing to wider, more rapid access to social safety net programs? Is it considering information about Long COVID when making public health risk calculations and decisions regarding mask mandates?

It seems that, instead of supporting the lives of the approximately 500,000 people experiencing Long COVID in New York City,[14] the city has chosen to turn the other way, and act like there is no crisis of chronic disease and disability ripping through its communities.

Over the course of this pandemic, it has been devastating to watch my community grow from 2.5 million to 12 million or more nationally.

Earlier this week, activists with ME/CFS and Long COVID gathered in Washington D.C.- to protest that the pandemic is not in fact over, and to demand that Long COVID and ME be declared the public health emergency that it is. I met 30 year olds who were runners 2 years ago, and are now in power wheelchairs. I met people whose voices or lungs were too weak to join in chants, who after 2 hours in the heat had to retire to bed for days, who are still in bed, 4 days later. This is my community, growing exponentially, and in crisis.

Overwhelmingly, my new community members are now experiencing what I experienced when first seeking help years ago: puzzlement or dismissal by the doctors that are supposed to care from them; marginalization by government and insurance programs that are supposed to protect and support those who are most vulnerable; and sometimes even rejection by families who do not understand why we can't just get out of bed and go back to work.

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[14] This is a very rough number. According to Household Pulse Survey data, 5.9% of people in New York state are currently experiencing Long COVID as a percentage of U.S. adults. Approximately 5.9% of the population of NYC is half a million.

I wouldn’t wish ME/CFS or dysautonomia on anyone. I developed it after a mononucleosis infection in college 13 years ago. 4 ½ years ago I had a severe exacerbation of symptoms and haven’t been able to work full-time since then. In 2017 and 2018, my energy impairment was so severe that I had to crawl to the bathroom on my worst days. I spent nearly every day in bed in a dark room. I had chronic migraines, severe light sensitivity, and disordered sleeping. My brain would not work. I could not concentrate enough to read, and even short conversations with my partner worsened my symptoms. Because of my dysautonomia, which is called postural orthostatic tachycardia syndrome (or POTS), when I took showers I had to sit down, because standing increased my heart rate to 160 bpm and I would have a severe crash afterwards. In that first year of unemployment, I began applying for social security disability. It took 1 1/2 years before I was approved. If I hadn’t had financial support from my partner and family, I could have easily been homeless.

This is a journal entry from when I was severely ill in 2019:

*Sometimes I’m able to read for an hour before my body falls under invisible weight. I’m unable to hold my head up to read the computer screen anymore, my brain mis-firing the more it tries to decode the words, 3 beats behind the sentence I just read, then 6, then 9. The skin around my eyes contracts and releases in quick, tight spasms. My head pulses with a deep, steady pressure that intensifies the more light streams in.The room spins around me from the nausea that follows. A deep ache like I just did sprints intensifies in my legs and arms.Sometimes I consider continuing to read anyways. But I know from pushing myself many times before that if I do, it only gets worse.*

*It takes all my effort - in moments like these - to turn my back from the screen and sink deeper into the couch. I bury my face in the cushion, shielding it from the light. My pounding heart beat contrasts with the leaden feeling in my limbs. Inside my skull is an unintelligible whir, like the hum of lightbulbs that just went black. I don’t know how long I’ll be like this. That’s always really scary. But panic only makes things even worse.*

*Many days at some point, when lying on the couch in our quiet, empty apartment, I can’t help but feel a deep loss flowing inside me. It’s like a hidden part of me holds a perennial funeral for the life I am not living. My still, recumbent body even resembles a corpse, the irony of which does not escape me. The tears stream down my cheeks and drip into my ears.*

Despite their severity and seriousness, only 6% of medical schools teach about post-viral chronic conditions like ME/CFS.[15] The majority of providers do not know how to screen for them, much less diagnose and treat them. So the millions of people now struggling with COVID-onset ME/CFS, dysautonomia and similar conditions simply do not have access to providers who know how to treat them, and this is disproportionately so for people of color, trans-people and non-binary people, and other groups who face especially high barriers when trying to access good healthcare. Without a diagnosis, securing social security and other benefits is much more challenging. This is a massive crisis in care and support.

Long COVID, ME/CFS, and similar complex chronic conditions - which affect women at higher rates than they do men - are under-researched, under-treated, and poorly understood in medicine. They present a women and gender equity issue. The history of medicine unfolds a centuries-long pattern of dismissing or psychologizing women's and non-binary people's very real physical symptoms, leading to inadequate study, gaslighting, and mistreatment by the healthcare system and by biomedical research institutions. People with Long COVID are now being misdiagnosed with depression and anxiety, as I was for the first 7 years of my illness. They are being dismissed or 'fired' by their doctors, they are being told to exercise their way out of their symptoms, when doing so could actually cause them more harm. The urgency with which treatments are being trialed for safety and efficacy for the unique subsets within this large disease population is non-existent.

Many providers think that ME/CFS and dysautonomia are useless diagnoses because there are no worthwhile treatments. I am here to tell you that is not true. While I am still disabled, I am no longer bedridden as I was 3 years ago, and I have gained more function and quality of life because of ME/CFS and dysautonomia interventions, including symptom-reducing medications (all off-label), prescribed by ME/CFS and dysautonomia-literate providers. I want everyone with Long COVID to - at minimum - have access to the care I have had, so they have the best chance (currently available in this area of medicine) of reducing or remitting their symptoms.

New York CIty and its public health agencies have an opportunity to break the cycle of neglecting or dismissing the many New Yorkers with complex chronic conditions developing from Long COVID. There is a huge need in New York City to track, educate, and take better care of people with Long COVID and associated conditions like ME/CFS.

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[15] Peterson, T., Peterson, T.W., Emerson, S.J., Regalbuto, E., Evans, M.A., & Jason, L.A. (2013). Coverage of CFS within U.S. Medical Schools. Universal journal of public health, 1, 177-179.

- Given its high prevalence, all public health campaigns and messaging related to COVID-19 in New York City should include information about Long COVID.
- Given its high prevalence in NYC, Long COVID and ME/CFS need its own widespread public health campaign, as too few New Yorkers know what Long COVID is, how to manage it, and resources to seek if they have it.
- We need major medical education efforts on Long COVID. All providers treating people with Long COVID should know the commonly occurring conditions of ME/CFS, dysautonomia, and MCAS, and be able to differentially diagnose and treat those. Provider education also needs to address gaslighting and unconscious bias.
- We desperately need enhanced data collection, to better understand the true impact Long COVID and associated conditions are having on individuals and communities.
- We need transparency, accountability from government officials and agencies, and substantial engagement between policy makers and those most affected by Long COVID and associated conditions.
- We need improved accommodations for workers, including domestic, contract, and gig workers, and wider access to disability coverage including for those workers whose jobs do not have the option of accommodations that meet their physical needs (for instance, because their jobs are physically demanding or have inflexible locations or work hours).
- We need rapid, comprehensive financial and other supports for those too sick to work or caring for those too sick to work.

We need the City Council, NYC DOHMH, and NYC H+H, to take action and put in place additional policies and programs and provide more support to those struggling with Long COVID and associated conditions.

We also need the city to take additional actions to prevent more people from getting COVID and Long COVID, as well as from getting reinfected and potentially getting worse. Vaccines are essential, but not enough on their own. We need a multi-pronged approach including mask mandates, free N95 masks, improved ventilation and filtration, and more.

**From:** Liz York <lizpaintsnyc@gmail.com>
**Sent:** Saturday, September 24, 2022 2:21 PM
**To:** Testimony
**Subject:** [EXTERNAL] On the need for Long Covid services

My experience at the Mt Sinai Long Covid Clinic highlighted the desperation of the staff and patients.

When I got the the office for my appointment, the line for registration was out the door. Checking in at the front desk was a slow process, and only one man was there to take care of many exasperated people.

Eventually, I was checked in. After I waited for 30 minutes, I was called over and told to come back in 2 hours because the Nurse Practitioner was running late. If I couldn't come back, I would have to wait 6 months for an appointment.

I came back and waited an additional 40 minutes before I saw the overwhelmed and frustrated Nurse Practitioner. She told me her staff is great, but they're all overworked.

The Nurse Practitioner said she sees people with my symptoms all day long, but she can't answer my questions. She gave me referrals to other doctors, and suggested compression stockings and Gatorade.

There were no doctors available at the clinic. There were no answers, just many frustrated people.

Please help. Long COVID deserves substantial new funding and resources on par with past HIV/AIDS efforts. There will be many more suffering.

Covid causes chronic fatigue.
MRIs show that brains shrink from the virus, affecting executive function- trivialized by the term "brain fog".
Problems persist with the vascular system, cardiac and respiratory system.

Covid has long term repercussions for the city's population and economy.

Please make covid care a priority.

Thank you,

Elizabeth York

Gold St,
, NY, NY 10038

My name is Elizabeth. I live in Brooklyn and work as a product manager at a large tech company.

I am here to voice my experience living with Long COVID following an initial infection that began on February 29th of 2020.

I would like to begin by giving you a sense of what my life was like before covid.

Prior to getting covid, I travelled to 19 countries across five continents. I organized multi-day and multi-week bike trips. I volunteered for nonprofits in the Dominican Republic and at the US-Mexico border. Closer to home, I volunteer taught software development to New York City high schoolers out of my company's office after work. I lifted weights, did Pilates, took hip hop classes, biked, ran, went hiking, and danced Cuban salsa.

Contrast that to today:

Today I am unable to walk for 15 minutes at a time without worrying about the potential negative repercussions. I now limit my walking to 8 to 9 minutes between any two points. If a distance is 10 minutes or longer, I will ride an electric scooter, which was purchased solely for this purpose, or take an Uber or Lyft. That should start to give you an idea of the physical limitations that I now have.

Since getting Covid, I have been diagnosed with dysautonomia, and ME/CFS, a disabling neuroimmune condition. I spend an inordinate amount of time managing my diet, supplements, medical appointments, and place extreme limits on how much energy I expend, both physically and mentally, just to maintain my fragile baseline. Going beyond these limits - which are far lower than any healthy person might expect - can result in sleep apnea, neuropathy, fibromyalgia-like pain, headaches, brain fog, and debilitating fatigue. There are individuals I know personally who pushed themselves past these limits and are now bedbound as a result.

There are two reasons that I am still able to work full-time. The first is that my job is 100% remote, my team is supportive, and I am able to take breaks whenever I need. The second is the full and unwavering support of my husband, who does the vast majority of our cleaning, shopping, and cooking, and walking and feeding our dog, in order to reduce the burden on myself.

Without these two lines of support, despite a bachelor's in mechanical engineering from Columbia, and a Master's in management science from Stanford, I can easily imagine myself on the verge of homelessness. When I applied to extend my part-time disability beyond six months, it was denied. I went back to work full time before I felt ready, and honestly believe that there is a possibility that I might have recovered by now, if I had been able to take an extended leave.

Since getting covid, I have seen over three dozen specialists. Many of these providers are out of network and the most helpful of them do not accept insurance. After what is covered by insurance, my healthcare-related expenses exceed thousands of dollars annually.

This was my experience, and I consider myself incredibly fortunate. I would be surprised if those in need of more assistance than I - would have had the time, energy, and resources to come here today.

There are no areas of policy that I'm aware of under the city council's jurisdiction that affect me personally.

I just hope to share my experience in case there's a way that it might help others.

Thank you.

**From:** Michael Owen <owenm7@yahoo.com>
**Sent:** Friday, September 23, 2022 6:10 PM
**To:** Testimony
**Subject:** [EXTERNAL] Long COVID/LT Covid Vaccine Syndrome - Long After Vaccination

Hello,

My name is Michael D. Owen of Woodlawn, Bronx NY 10470.

I saw your meeting on *Gothamist* and felt the need to share my portion of the LT Covid story.

I have been gaslighted medically - including initial Gastro who wanted to hospitalize me no reason - for 'Anxiety' because I strongly disagreed with his blame first, lack of emergency level help for severe physical/Gastro trouble out of nowhere.

Cornell Downtown - "Hypothesis: Long Term Covid Syndrome induced by Vacines - Long After Vaccination."

Columbia Med: same - tacitly agree but not enough data.

History with Vaccination (Moderna 1 and 2 - Booster was Pfizer:

1) Feb 2021 - within 48 hours 6 days worst FLU of my life- only could get sips of water down

2) March 2021 - within 48 hours my PTSD/Anxiety shot to ALL TIME HIGH and after testing negative -I was sent to Montefiore Moses ER for a "10 Min Psych Evaluation" I waited near 10 hours in Covid and Violence to be told by child Resident "I have no idea" and given same tired list of Bronx psych help. Symptoms later: Brain fog, confusion, extreme exhaustion, Neuro: Tripping, Falling, Breaking things (falling on breakfast tray - many coffee cups broken in 'spasms.'), falling on stairs, falling on street.

3) Dec 9, 2021- within 48 hours I began PROJECTILE VOMITTING (never happened) - and was so violent I was CHOKING on the speed and volume. I slept upright in a chair to not choke. Put on naseau RX (Union allows 9 pills per month - that's it). I end up on flu diet, no solid meals since 12.2021, lost 20+ lbs - and lost all movement/motilty in digestion to EXTREME.
I've had 4 tests at Columbia Med, will have 5th - and they want lower stomach physical therapy. No one will go on record but maintain how bad health became after each vax.

I have found no Pubilic or Private Hospitals or Clinics that help people like me - and there are MANY of us (a 275 lb man behind me in small grocery had to have EMS come pick him up off floor of his home - 48hrs post Vax 2). In the barbershop - many injured and/or LT sick- every time they got vaxed. We believe the 'gaslighting' and lack of help is because - no one can say Vaccines can be harmful. For many (I'm sure millons) - they absolutely were.

I'm imploring the City of NY to look into and treat myself and others - instead of circurlar hand offs to no help clinics, Blame, or "I DONT KNOW" while I struggle with way worse mental health - because my physical health at 51 - has never been WORSE.
That is because I got 3 no choice overpowerful, damaging Vaccines - that have pushed me to brink with Blame -and lack of real Help/Understanding.

Thank you,

Michael D. Owen
Woodlawn, Bronx NY

Hello, my name is Rachel Robles. I am a New York City resident, a Latina with disabilities, and a member of patient advocacy organizations such as Body Politic and Patient Led Research Collaborative. I am here to voice my experience living with Long COVID for the past two and a half years, and to call on City Council, DOHMH, and other city agencies to better meet the needs of the many New Yorkers struggling with Long COVID and the complex chronic conditions and disabilities it can create.

I became ill with Covid-19 in March 2020 just as the pandemic was taking hold in NYC. Hospitals were overflowing, and young people without serious preexisting conditions were being told to stay at home. I utilized virtual urgent care and received reassurance from doctors that I had been "spared from the worst of it." They urged me to sit at home and wait it out. **Since then, over two years have passed. I am still waiting it out.**

Two months later, I searched for specialists with expertise in infectious diseases, and felt defeated after receiving diagnosis after diagnosis of anxiety. Initially, I was given a clinical diagnosis of COVID-19 because I didn't have access to testing. Suddenly, though, the very symptoms that had informed that diagnosis were weaponized against me. On one visit to an infectious disease specialist, I was told, "COVID-19 doesn't last for ninety days. You either get over it, or you die."

**This is the grim reality of the Long COVID experience, especially for marginalized groups who lack access to quality testing and care.** In the months and years following my infection, I have had to advocate **against** these diagnoses of somatization and **for** every thoughtful diagnosis I've received, all while dealing with symptoms of brain fog that cause difficulty understanding conversations and confusion about where I am when I walk through my neighborhood.

I have worked tirelessly to make my symptoms manageable, **but unfortunately I still have to endure them incessantly.** I developed sensitivity to screens that leads to head pressure, migraines, and tinnitus, which means I have to pace my screen time throughout the day in order to not trigger symptoms. Additionally, my organ dysfunction and damage now makes me immunocompromised. I have to take extreme measures or completely avoid being with others, sometimes prolonging my healthcare and recovery as a result. Since my acute infection, I have been diagnosed with autonomic dysfunction, chronic migraines, acute hepatitis, and even a brain injury, and have undergone treatments as simple as implementing breathing exercises all the way to flying across the country to do neurological rehabilitation.

While I'm disclosing a very vulnerable and tumultuous journey I've endured, I feel it's important to stress that our stories are not here to elicit pity, nor be an inspiration. They're here to ignite the fire, passion, and anger that are needed to **reform the oppressive systems I and many others battle every day**. They're not here for your blanket apologies or your praise. They're here for your advocacy, your policies, your congressional actions.

In a world that tries to ignore disability, we refuse to be ignored.

**"The Gendered Impact of Long COVID"** – Thursday, September 22nd, 2022

Committee on Women and Gender Equity + Subcommittee on COVID Recovery and Resiliency

Below is the transcript of oral testimony given by Gabriel San Emeterio on behalf of a fellow advocate, a 30-something cis, straight, white woman from New York City, who wishes to remain anonymous due to the stigma surrounding Long COVID and impact it could have on her career. Below said transcript is a longer submission by the same anonymous advocate for the hearing record:

<u>Transcript</u>:

My gender has played a huge role in my Long COVID story. Given time constraints, I'd like to share only a few examples:

- First, I was infected with COVID in March 2020 while picking up my "non-essential" and thus "undeliverable" birth control at a nearby chain pharmacy. Perhaps my life would be different if I had risked an unintended pregnancy.
- Second, before I developed COVID symptoms, like many mothers of young children, I was sleep deprived. A recent study has shown that poor sleep prior to COVID infection increases the chance of Long COVID by <u>up to 3.5 times</u>. I expect I am not the only parent whose accumulated sleep deficit impacted their illness.
- Third, I "pushed through" my acute COVID symptoms due, in large part, to family caregiving responsibilities. I spent the days following my three days of flu-like symptoms juggling full-time remote work and full-time childcare rather than <u>resting</u>.
- Fourth, I also "pushed through" my early Long COVID symptoms due to medical gaslighting. My primary care provider, despite <u>repeatedly</u> hearing my frightening symptoms, <u>only</u> provided a psychiatry referral for anxiety and a basic bloodwork order.
- Fifth, I was only <u>recently</u> diagnosed with many life-long illnesses that are common in women, like hypermobile Ehlers Danlos Syndrome and POTS, that pre-COVID doctors misdiagnosed as "functional neurological disorder", once known as "conversion disorder" or "hysteria". lf more clinical education was provided regarding these under-diagnosed illnesses, I would have received <u>appropriate</u> medical attention prior to COVID that would have lessened the impact of COVID.
- Sixth, I'm overpaying for inadequate treatments for these life-long illnesses because these conditions historically and primarily affect women and are thus grossly underfunded and studied.
- Last, I still have <u>no idea</u> if any of my reproductive decisions were correct in relation to Long COVID. No doctor has confidently told me what effect breastfeeding with Long COVID could have on my child, or what effect pregnancy would have on me. This lack of information is especially galling given the large number of longhaulers who are of childbearing age and capacity.

We deserve informed post-viral medical care free of sexist medical gaslighting, relief from applicable caregiving responsibilities and research into the specific interplay between reproduction and post-viral illnesses so that we can make informed decisions. And all longhaulers deserve recognition, good medical care, job accommodations, supportive services and financial support. I ask the Council to help us in any way it can. Our lives and futures, as well as those of our families and communities, depend on it.

Written Submission:

I was infected with COVID at a Queens pharmacy while picking up my birth control in pre-lockdown March 2020. I had tried, without success, to have the medication delivered, but the pharmacy would not deliver "non-essential" refrigerated medicine. Perhaps I wouldn't have a story to tell if I had been comfortable with risking an unintended pregnancy during the early days of a pandemic.

In the nine days between infection and illness, I couldn't sleep. I felt a sense of impending doom (which may have been early autonomic dysfunction) as I stayed up late to secure grocery deliveries and consoled my confused toddler. Two-and-a-half years later, I can only wonder if I, like many parents (and especially mothers) of young children, never stood a chance, as a recent study has indicated that poor sleep quality prior to COVID infection increases the risk of Long COVID by 3.5x.[1]

Once I developed COVID symptoms - about three days of flu-like symptoms and two weeks of intense fatigue - I nevertheless "pushed through", attempting to both work full-time from home in my professional services job and care for my child, whose daycare had closed. I believed my symptoms "mild" and anticipated they would resolve in the reported two-week period.

But immediately after those two weeks, I began to experience weird and alarming symptoms - memory loss, difficulty concentrating, headaches, facial numbness, vision changes, joint pain and bulging veins. I described my symptoms to and shared my concerns with my primary care provider over the course of several telehealth visits in April and May 2020, but her proposed care plan only included a psychiatrist referral and the offer to run some bloodwork in the future. Textbook medical gaslighting.

In hindsight, my fate was sealed with my PCP long ago – I had been diagnosed with functional neurological disorder ("FND"), once known as "conversion disorder" or, famously, "hysteria" back in 2013, after I had biannual summertime episodes of unexplained pain or numbness (symptoms that I now believe are consistent with my current diagnoses). So, upon presenting myself to her with "yet another" assortment of symptoms, I was dismissed, like all too many women, as anxious and, for me, having another FND episode. (And, I must say: Wouldn't you be anxious if you had just been sick with a novel virus and told by doctors that you would receive no medical treatment unless you turned blue?)

But I digress: by summer 2020, although I had found several other doctors who listened to and believed my story and recognized commonalities with other patients now known as "longhaulers", their preliminary treatments were insufficient to restore me to my prior health and lifestyle. I simply did not have the energy to work full-time or care for my toddler and home, let alone do all three, and as a result my health continued to decline. By early 2021, I could not multitask, rely on my short-term memory, drive, do more than one chore per day or leave my home, including to take my child outside; I was only working at about half-capacity. My spouse, in addition to working full-time, had to take on almost all of the household and childcare responsibilities.

Due to debilitating fatigue, I had to take an extended leave of absence from work, during which I developed entirely new neurological symptoms after receiving my first COVID vaccine that left me unable to read, look at screens or tolerate light or sound. Thanks to supportive doctors and new medications and treatments, I have gradually increased my workload and work-related stamina. When I first started back to work, I couldn't look at the computer for more than 20-30 minutes without getting so dizzy and fatigued I would need to lie down in a dark room for 15 minutes, but I now can work an almost-full day with intermittent breaks. On the personal front, I've moved from being unable to read children's books or go outside with my child to being able to resume limited weekend outings to the farmer's market and

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[1] https://bmcpublichealth.biomedcentral.com/articles/10.1186/s12889-022-14123-7

playground. But the changes, albeit happy, have been difficult: when I took my child to the playground for the first time in over a year, I cried because I didn't know what to do and couldn't keep up without my heartrate doubling.

Even though I'm much more stable than I was last year, it takes 20 medications (only 3 of which are covered by insurance) and 5 medical therapies (none of which are covered by insurance) every day to manage the many conditions I've been diagnosed with since contracting COVID, including Long COVID, myalgic encephalomyelitis / chronic fatigue syndrome (ME/CFS), postural orthostatic tachycardia syndrome (POTS), hypermobile Ehlers-Danlos Syndrome (hEDS), histamine intolerance (a limited version of mast cell activation syndrome (MCAS)), cranio-cervical instability (CCI), Hashimoto's Thyroiditis, reactivated Epstein-Barr Virus and migraines. These are all lifelong, underfunded, understudied conditions that are common diagnoses for longhaulers and others with infection-related chronic illnesses. We need so much more support and funding if we are to have any real hope of solving Long COVID and these associated illnesses (most of which predominantly affect women).

One thing I haven't mentioned yet is the lack of care I've received, even from my otherwise "good" doctors, regarding my child-bearing decisions as a longhauler. I have never received real advice as to whether breastfeeding my child was safe, advisable and/or would have any effect on my symptoms or prognosis, even though sex hormones are thought to have a not-immaterial impact on COVID and Long COVID severity and outcomes. Similarly, I have yet to receive good counsel as to the effect any future pregnancy might have on my health and status as a longhauler. The ME/CFS community (to which approximately 50% of people with Long COVID belong) has anecdotal data that pregnancy has a good chance of triggering ME/CFS remission, but there is bafflingly little research into this seemingly-life changing matter, especially since a large number of people with Long COVID are people of child-bearing age and capacity.

In telling you my own story, I must note that, although I've experienced many not-atypical barriers to care based on my gender, I'm not representative of many longhaulers. I have good health insurance, good doctors (including specialists with long waiting lists who don't accept insurance), a supportive employer who has approved every reasonable accommodation request I've made, private long term disability benefits that have replaced most of my lost income, two lawyers to assist with claims, financial resources to try out all kinds of supplements and products, an incredibly supportive spouse and the general privilege of being a cis, straight, white person.

It shouldn't have to be this way. Anyone can become a longhauler as sick as I have been, and everyone who becomes a longhauler deserves recognition, good medical care, job accommodations, supportive services and financial support. Women, in particular, deserve informed post-viral medical care free of sexist medical gaslighting, relief from applicable caregiving responsibilities and research into the specific interplay between reproduction and post-viral illnesses so that we can make informed decisions. I ask the Council to help us in any way we can. Our lives and futures, as well as those of our families and communities, depend on it.

I am a third generation New Yorker, New York City resident, mother of elementary school age children, and a dedicated public servant in city service for well over a decade.

I am here to voice my experience living with Long COVID, and to call on City Council, DOHMH, and other city agencies to better meet the needs of the many New Yorkers struggling with Long COVID and the complex chronic conditions and disabilities it creates.

I also call on these agencies to immediately adopt flexible work options (including telework) to better support those like myself.

Outdated, inflexible work policies inflict an outsize burden on women, disabled, caregivers, and people of color, but flexible work can alleviate this impact on individuals who are disproportionately leaving the workforce.

A flexible work option would increase diversity and inclusion in the city workforce, increase employee productivity, promote employee retention, and maintain competitiveness and equity with other government entities and the private sector.

As a municipal employee, I returned full time to my physical office at the mandate of the administration and (despite being vaccinated) contracted COVID-19 in January of 2022 during the extreme surge at my workplace and throughout New York City.

I immediately saw how the mandatory return to office (and lax implementation of COVID protocols) contributed directly to the surge and on the ability to deliver necessary services to New Yorkers.

As a working parent, contracting COVID -19 had an immediate impact on my job and my family.

Despite being sick with debilitating headaches, chills, nausea, dizziness, fever, blurry vision, brain fog, and extreme body aches, I had to take care of my minor children and continue to try and work from home. As a member of a workplace with severe attrition, my inability to work had a crippling effect on New Yorkers.

Contracting COVID-19( upon my return to my physical workplace) forever changed the trajectory of my life. To this day, my health has not returned. I am not the healthy person I once was.

To compound the issues surrounding my deteriorating health, despite the assurance of flexibility for caregivers and those with disabilities, the administration has taken a hard stance on a full return to physical offices without flexible options.

Mayor Adams said in his primary campaign: “Covid has shown that we do not all need to be at a desk in an office building to be productive. This is why I will encourage more flexible work options and remote work across the City so that caregivers can continue to care for their families while maintaining employment.”

Unfortunately, for those of us caregivers facing long haul COVID, this promise has not become a reality and we are faced with the hard choice of caring for our health, our children, or leaving the municipal workforce.

Months of treatment and long haul COVID-19 doctors can not undue the harm caused to my body by this virus.

It is only with continued treatments and extreme care that there could be hope on the horizon, but my future is unclear.

I ask for advocacy and resources for those like myself, dedicated public servants, caregivers, and life long New Yorkers, who need help. Thank you.

# THE COUNCIL
# THE CITY OF NEW YORK

*Appearance Card*

I intend to appear and speak on Int. No. ______ Res. No. ______

☐ in favor ☐ in opposition

*Date:* ______

(PLEASE PRINT)

Name: Gabriol San Emeterio

Address: 10036

I represent: Dr. Susan Levine (expert)

Address:

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# THE COUNCIL
# THE CITY OF NEW YORK

*Appearance Card*

I intend to appear and speak on Int. No. ______ Res. No. ______

☐ in favor ☐ in opposition

*Date:* Sep. 22 2022

(PLEASE PRINT)

Name: Kenya Williams

Address: [redacted] Sackman Street

I represent: Caroll Gardens Association

Address: 201 Columbia Street

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# THE COUNCIL
# THE CITY OF NEW YORK

*Appearance Card*

I intend to appear and speak on Int. No. ______ Res. No. ______

☐ in favor ☐ in opposition

*Date:* 9/22/22

(PLEASE PRINT)

Name: Elizabeth Martin

Address: 11201

I represent: myself

Address:

*Please complete this card and return to the Sergeant-at-Arms*

# THE COUNCIL
# THE CITY OF NEW YORK

*Appearance Card*

I intend to appear and speak on Int. No. ________ Res. No. ________
☐ in favor ☐ in opposition

*Date:* 9/22/22

**(PLEASE PRINT)**

Name: Gabriel San Emeterio
Address: 10036
I represent: Anonymous testimony (mother)
Address:

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# THE COUNCIL
# THE CITY OF NEW YORK

*Appearance Card*

I intend to appear and speak on Int. No. ________ Res. No. ________
☐ in favor ☐ in opposition

*Date:* 9/22/22

**(PLEASE PRINT)**

Name: Gabriel San Emeterio
Address: 10036
I represent: Anonymous testimony (City worker)
Address:

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# THE COUNCIL
# THE CITY OF NEW YORK

*Appearance Card*

I intend to appear and speak on Int. No. ________ Res. No. ________
☐ in favor ☐ in opposition

*Date:* 9/22/22

**(PLEASE PRINT)**

Name: Gabriel SanEmeterio
Address: [redacted] West 42nd st. [redacted], 10036
I represent: Self
Address:

*Please complete this card and return to the Sergeant-at-Arms*

# THE COUNCIL
# THE CITY OF NEW YORK

*Appearance Card*

I intend to appear and speak on Int. No. ________ Res. No. ________

☐ in favor ☐ in opposition

*Date:* ________

**(PLEASE PRINT)**

**Name:** Ted Long

**Address:** 50 Water St

**I represent:** NYC H+H

**Address:** 50 Water St

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# THE COUNCIL
# THE CITY OF NEW YORK

*Appearance Card*

I intend to appear and speak on Int. No. ________ Res. No. ________

☐ in favor ☐ in opposition

*Date:* 09/22/2022

**(PLEASE PRINT)**

**Name:** Celia Quinn, MD MPH

**Address:** Deputy Commissioner - Disease Control

**I represent:** DOHMH

**Address:** ________

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