CITY COUNCIL
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TRANSCRIPT OF THE MINUTES

Of the
COMMITTEE ON WOMEN AND GENDER EQUITY
JOINTLY WITH THE SUBCOMMITTEE ON COVID RECOVERY AND RESILIENCY
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Thursday, September 22, 2022
Start: 1:52 P. M.
Recess: 4:32 P. M.

HELD AT: 250 Broadway - Committee Room, 16th Floor

B E F O R E: Hon. Tiffany Cabán, Chair
Hon. Francisco Moya, Chair

COUNCIL MEMBERS:

Althea V. Stevens
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COMMITTEE ON WOMEN AND GENDER EQUITY
JOINTLY WITH THE SUBCOMMITTEE ON COVID RECOVERY AND RESILIENCY

A P P E A R A N C E S

Dr. Celia Quinn,
Deputy Commissioner of Disease Control at the NYC Department of Health and Mental Hygiene

Dr. Ted Long,
Senior Vice President for Ambulatory Care and Executive Director of NYC Test & Treat at New York City Health + Hospitals

Dr. Lawrence Purpura,
Assistant Professor of Medicine and Infectious Diseases Specialist at Columbia University Medical Center

Namrata Pradhan,
Organizer at Adhikaar

Rukamani Bhaattarai,
Domestic Worker Leader at Adhikaar

Lisa Bernstein,
Hand in Hand: The Domestic Employers Network

Kenya Williams,
NYC Coalition for Domestic Work; Member of Carroll Gardens Association

Elizabeth Martin,
Product Manager at Salesforce; New Yorker living with Long COVID

Dr. David Putrino,
Director of Rehabilitation Innovation for Mount Sinai Health System

Ed Yong,
Science Journalist; Staff Writer at The Atlantic

COMMITTEE ON WOMEN AND GENDER EQUITY
JOINTLY WITH THE SUBCOMMITTEE ON COVID RECOVERY AND RESILIENCY

A P P E A R A N C E S (CONTINUED)

JD Davids,
Co-founder at Network for Long COVID Justice/ Strategies for High Impact

Kimberleigh Smith,
Senior Director of Public Policy and Advocacy for Callen-Lorde Community Health Center: *Speaking on behalf of* Elsbet Servay, Family Nurse Practitioner at Callen-Lorde Community Health Center

Juan Pinzon,
Director of Health Campaigns and Government Engagement at Community Service Society of New York

Mae Smith,
Executive Director at NYC Administration for Children's Services

Dr. Anthony Komaroff,
Professor of Medicine at Harvard Medical School

Gabriel San Emeterio,
Co-founder of Strategies for High Impact and its Network for Long COVID Justice, *Testifying on Behalf of:* Themselves, Anonymous Witnesses One and Two, and reading Dr. Susan Levine's Testimony into the record.

Therese Russo,
Long COVID Advocate with the National Network for Long COVID Justice - NY, and the New York State Chapter Leader for #MEAction

Myra Batchelder,
Health Policy and Advocacy in NYC

Rachel Robles,
New York City Resident and a member of patient advocacy organizations [such As Body Politic and Patient Led Research Collaborative]

SERGEANT LUGO: This is a microphone check, today's date is September 22, 2022, on The Committee on Women and Gender Equity jointly with the Subcommittee on COVID Recovery and Resiliency located on the 16th floor, recorded by Pedro Lugo.

SERGEANT AT ARMS: Good afternoon, and welcome to today's New York Council Hearing on Women and Gender Equity jointly with the Subcommittee on COVID Recovery and Resiliency. If you wish to submit testimony, you may do so at testimony@council.nyc.gov. At this time, please silence all electronic devices, and thank you for your cooperation. Chairs, we are ready to begin.

CHAIRPERSON CABÁN: Thank you.

[GAVELING IN] [GAVEL SOUND]

Good afternoon, everyone, my name is Tiffany Cabán, my pronouns are she/her, and I am the Chair of The Committee on Women and Gender Equity. I would like to give an opening statement, and then I will hand it over to our co-chair today.

The President has declared the pandemic over. The Governor's public health policy is "you do you", but for millions of our people, especially women, COVID continues to represent an urgent threat of

death, disability, illness, and suffering. Yesterday alone COVID claimed the lives of at least 916 Americans. And if we were to do a minute of silence for each of them, this hearing would not be able to start until around 5:00 in the morning. We lose about a 9/11's worth of Americans every week to COVID, with this year's excess death rate on track to match last year's. And the thing is, the death rate isn't the only danger COVID poses.

Today, we are here to talk about the facet of this viral disease that is just as horrific -- Long COVID. It afflicts the young and old alike, the sick and healthy alike, the vaccinated and unvaccinated alike, and symptoms can last years. There is no known cure for it, and as Time Magazine put it this week, quote, "The only way to prevent it is to not get infected at all."

And with new highly diverged variants poised for ImmunoScape popping up all of the time, our vaccine response is likely to continue struggling to catch up indefinitely. We will be particularly looking at its gendered impacts, but deficit to say, Long COVID is a pandemic unto itself. Public health scholars vary on how many COVID survivors are plagued

by ongoing symptoms -- some estimates put the figure as high as one out of every three. But even if only 5% were afflicted, that would total 7.5 million Americans -- 7.5 million. And for context, approximately 1.8 million Americans are diagnosed with cancer every year; 1.5 million with diabetes, and Harvard economist David Cutler estimates that as many as three 3.5 million American workers are out of work due to Long COVID costing our economy $3.7 trillion total. As for the gendered impacts, according the World Health Organization, women are twice likely as men to experience Long COVID. And, why is it so much more likely in women? It's because women bare... Is it because women bare a disproportionate amount of the childcare, housework, and social reproduction burdens, and therefore, cannot get the clinical rest necessary to fully recover? Are there immunological differences linked to sex or the social determinate of gender? Are there other possible explanations we are currently unaware of?

And today, we hope today find out what we know, what we suspect, and what we need more research on. But, what is clear; however, is that greatly more

women than man continue to experience symptoms well after they stop testing positive for COVID. And what are those symptoms? It's basically everything.

Long COVID can affect your heart; a study this month in an international journal found that 73% of COVID survivors had cardiac signs and symptoms more than three months after infection, and 57% still had them at nearly one-year.

Long COVID can affect your brain. A study of more than six million patients 65 and older published in The Journal of Alzheimer Disease, found that the risk for developing Alzheimer's increased by 50 to 80% in older adults who caught COVID-19 within a year.

The CDC has found that Long COVID can increase your risk of strokes, neuropathy, asthma, diabetes, pulmonary embolism and other thrombotic disorders, and the list goes on and on.

Quiet as it is kept, this is indisputably a mass disabling event, and possibly the longest one in history.

So, again, a reminder that every terrible aspect of Long COVID is twice as prevalent in women. And that is one of the main reasons our elected leaders,

prominent medical personalities, and corporate medial rarely ever mention Long COVID.

The members of this committee are intimately familiar with how often women are dismissed by doctors -- told that their symptoms are all in their head, and made to question their sanity. And, once upon a time, they would proclaim a diagnosis of hysteria. And now they use more polite words, but it all adds up to the same thing, if it's women who suffer more, it's easier to ignore.

But there is another related factor at play here, why when given the scope and depth of the threat, are elected leaders shredding every last public health protection we ever put in place? And the reason is simple, they are doing the bidding of the corporate ownership class, overwhelming men, whose windfall profits depend on forcing working people, predominantly women, to commute and work in dangerous conditions. And it's a choice to prioritize profits over people -- period.

If we care about New Yorkers, if we care about the disability community, if we care about women and our transgender, gender fluid, non-binary, and gender non-conforming neighbors/friends/family, we will

treat this topic with much more seriousness and compassion than the billionaire folks running our city, running our country, and running our loved ones into the ground.

And, so, I want to thank everyone here for joining us today for this hearing. And with that, I will pass it to Council Member Moya for his opening remarks.

CHAIRPERSON MOYA: Thank you, and, uh, good afternoon, thank you, Chair Cabán.

I Council Member Francisco Moya, I am the chair of the Subcommittee on COVID Recovery and Resiliency. I would like to thank, uh, my co-chair and my colleagues for being present here today for this important discussion.

Since the City's first confirmed case of COVID-19 in February of 2020, the number of New York City residents that have been infected total is almost 3 million.

There is no denying that the pandemic has had a profound effect on each every one of us. While there is still much to learn about the effects of the virus, we do know that its impact can last longer after a person's recovery from the infection.

According to the CDC, one in 13 adults in the United States currently experience Long COVID symptoms, which is defined as symptoms lasting three or more months from after the virus is first contracted.

This past June, The COVID Subcommittee held a joint hearing with The Committee on Hospitals on long-term COVID treatment in New York City Hospitals. Today we are here to address what is now referred to as Long COVID Syndrome. While millions of dollars are currently being spent to study this in general, research has found that women are significantly more likely than men to develop the symptoms associated with Long COVID. A March 2022 study published in the Journal for Women's Health found that a larger portion of women who had COVID had lingering symptoms compared to men for an average of five months after initial infection. Women are significantly more likely to report persistent weakness, altered smell and taste, and shortness of breath, palpitations, and muscle pain. Experts say that this difference in symptoms may be because women in general have stronger immune systems, the disparate response may appear because the woman's immune system reacts more

robustly and rapidly, which can protect from an initial severe infection, but it can render women more vulnerable to prolonged autoimmune related diseases. These are some of the explanations we are hoping to explore in more detail with the experts on Long COVID who have kindly joined us for today's hearing.

As the rest of the world moves on, we must continue to focus on -- and take seriously -- the long-term effects that this virus has had on the health of New Yorkers, especially those without social safety nets.

Preliminary data shows that the negative impact of Long-term COVID extends far beyond health. It impacts a person's ability to work and maintain social relationships. The City and the country as whole must be vigilant in identifying, uh, the gender impacts on Long COVID, and to consider the ways in which women, transgender, gender non-conforming individuals are uniquely affected by this virus. Women are the backbone of our society and are suffering, and we cannot ignore their cries for help.

I want to thank the administration for being here today, and I look forward to our discussion on this

important issue. Again, I want to thank Chair Cabán once again, as well as the Subcommittee on COVID Recovery and Resiliency, and I want to thank, uh, my committee staff for their work in this issue, uh, Harbani, Sarah, and also Mahnoor, as well as my Chief of Staff, Meghan Tadio, and Phiveline Solano.

I now turn this back to Chair Cabán.

CHAIRPERSON CABÁN: Thank you, uhm, and with that I'd also like to thank my staff for their hard works: Steph Silkowski, my Chief of Staff; Madhuri Shukla, Legislative and Budget Director; and Jesse Myerson – Director of Communications; as well as the committee staff for their work in this hearing: Brenda McKinney, Senior Legislative Counsel; Anastassia Zimina, Legislative Policy Analyst.

And before we move to Dr. Levine, who will testify before the administration today, I want to welcome the students who are here today, uh, and also recognize my colleagues present for the record: Council Member Narcisse, Council Member Riley, Council Member Brooks - Powers, Council Member Rivera, and Council Member Stevens, and Council Member Gennaro, who is with us virtually -- I hope you are feeling better.

COUNCIL MEMBER GENNARO: Long COVID is a pain in the ass, and that's what I have.

CHAIRPERSON CABÁN: Ugh.

COMMITTEE COUNSEL: We appear to be having technical difficulties, we'll give her one minute.

CHAIRPERSON CABÁN: Okay. And, we are just going to wait about one minute, uh, Dr. Levine is currently trying to get on to the Zoom. I appreciate folks' patience, thank you.

CHAIRPERSON CABÁN: And, if there is anybody here that wants to testify today, just make sure that you speak to the sergeant, and fill out one of the Appearance Cards, thank you.

SERGEANT AT ARMS: If you are in person and you've registered to sign in online to testify, you also have to sign in at the desk.

CHAIRPERSON CABÁN: And I would just like to acknowledge that we have been joined by Council Member Brewer.

COMMITTEE COUNSEL: Hi, everyone, thank you for your patience. We are experiencing a technical difficulty, and the witness is trying to log in. So, it should just be one minute, thank you for your patience.

COMMITTEE COUNSEL: Everyone, thank you again for your patience. This is the hearing on The Gendered Impact of Long COVID with The Committee on Women and Gender Equity and Subcommittee on COVID Recovery and Resiliency.

We will wait one more minute to try to facilitate these issues. Uhm, we have been working behind the scenes on them, and then move on if we can't do that. So, thank you very much we appreciate your patience.

CHAIRPERSON CABÁN: Alright, thank you, we are going to move to admin testimony.

COMMITTEE COUNSEL: Thank you, Admin, for being here. Will you please raise your right hand?

Do you affirm to tell the truth, the whole truth, and nothing but the truth, before this committee, and to respond honestly to council member questions?

DEPUTY COMMISSIONER QUINN: I do.

SENIOR VICE PRESIDENT LONG: I do.

COMMITTEE COUNSEL: You may begin.

DEPUTY COMMISSIONER QUINN: Thank you, 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 mentioned, 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 highlighting 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 City 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. This 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 crucially important that we ensure New Yorkers know about the possibility of developing Long COVID, that they 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 healthcare 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.

CHAIRPERSON CABÁN: Thank you.

So, I think I want to start with, uhm, following up on some of your testimony where you lay out that there have been educational efforts as well as different kinds of communications using different kinds of mediums. I would like to dig in on both of those pieces a little bit.

What are you existing programs on Long COVID, and what are the existing programs across New York City, and what are the current and long term plans to help the growing number of people with Long COVID?

DEPUTY COMMISSIONER QUINN: Thank you. So, The Health Department's efforts, especially with our public health corps and community based organizations that we work with, and our public communication is really about raising awareness so that people who are experiencing symptoms after COVID know that they should be seeking care and that care is available for them.

I would like to it over to Dr. Long to talk a bit about the specific clinical services that H+H is offering... (CROSS-TALK)

CHAIRPERSON CABÁN: Yeah, and... And... And, to add to that question, to get more into specifics, just, also what kinds of resources are being put into this? Like a dollar number, right? Because, like I said, we are doing education, but if we are not doing at the scale where we are reaching enough people, like, that's a question for concern as well.

SENIOR VICE PRESIDENT LONG: Yeah, so, hi, I just want to start by saying thank you for having us today. And thank you for bringing up this extremely important topic.

I am a primary care doctor in The Bronx [INAUDIBLE] practicing tomorrow, and too many of my

patients today have Long COVID. So for me, this is a personal, very important issue that we need to address immediately as a cornerstone of our city's recovery.

So, I want to talk about two programs that we have that address Long COVID. The first is our AfterCare Program, which is a city program. And, the second program is our COVID Centers of Excellence, which are something that we early knew would be important that we uniquely created in New York City.

For AfterCare in terms of some of the numbers, so AfterCare is program that we created awhile back when we were first learning about Long COVID, knowing that this would be a very important thing to help our city, where we proactively were going to reach out to people that had had COVID before, see who was still potentially suffering from symptoms related to COVID -- or could have Long COVID -- and bring them in for whatever it is that they would need. Since then, the program has evolved so that you can actually call 212-COVID19 and speak with one of our navigators with a direct connection there. But, what our navigators, whether we are reaching out to you or whether you're calling us will do, uh, is we will talk to you about

what's going on with you. Uh, for a lot of people, to the number one thing people need is a referral for more medical care at one of our COVID Centers of Excellence. The reason that is important, is for my patients I see in The Bronx every Friday who have Long COVID, I do my best to take good care of them. I care about them, but I worry about people that don't have me as their doctor. What about all of the New Yorkers that are suffering in silence because they don't know how to engage with the healthcare system, or they can't make sense of these symptoms they're having, which can be confusing. So referrals to one of our Centers of Excellence can help to resolve that. Other types of discussions that are AfterCare Navigators have with people is that we also offer mental health, financial assistance, help with utilities, help with housing, and we finally offer, uhm, a community through Body Politic, because a lot of... And, this is what my patients tell me all the time, is that what they are experiencing frightens them. And for a lot of people it's human nature to want to be around other people that are going through something similar. So, Body Politic is a community support group and organization that enables people to

come together. So, the AfterCare Program, we started off by reaching out, we sent hundreds of thousands of texts and phone calls to former cases or people that formerly had COVID , with the focus on our Taskforce on Racial Inclusion and Equity Neighborhoods. We spoke with those people, and we actually reached more than 230,000 of them, and then we made connections with them for whatever the resources that they needed were. And, again, it varied person to person. Some people needed medical care, some people needed financial support. Right now, the status of AfterCare is it's still very active. We are still reaching out to people and you can, again, call 212-COVID19 to speak with an AfterCare Navigator today.

So, one of the things that we want to make sure we focus on is that we have enough AfterCare Navigators based on the need that we are seeing in our communities for Long COVID. We are in a great position now, but that's something that we want to have a key focus on in terms of, uh, making sure that we have the future resources in place to take care of people with COVID. Uh... (CROSS-TALK)

CHAIRPERSON CABÁN: How many navigators are there? And in your opinion, how many do we need to meet the current needs?

SENIOR VICE PRESIDENT LONG: Yeah, so, I would say we need as many navigators as we need to be able to pick up the phone when people call us and to be able to make outbound phone calls. Right now, you can try yourself, uh, somebody will pick up the phone almost immediately when you call 212-COVID19. And there is a press-off for one of our AfterCare Navigators. We have hundreds through three organizations, two community based organizations, BronxWorks and the Chinese-American Planning Council.

So, this is something we keep a key focus on, but right now we are definitely able to meet the need that we are seeing, and our goal is to make sure that we are proactively giving every New Yorker who has had COVID, and who has these symptoms, which can be scary, a place to go, and a place to get answers, and a place to feel support.

Our Centers of Excellence -- I'll be very brief -- these are clinical centers that we have opened of three of them over the last year... one to two years.

You asked about costs, we spent $140 million constructing these three Centers of Excellence. But, the important part there, is that we did six years of constructing these state of the art medical facilities, six years worth of work, in six months. Because we cannot wait six years to care of our New Yorkers with Long COVID. We have to take care of them now. So, we were able to accomplish that, which is no small feat.

Now we are accepting patient; we have completed more than 20,000 visits across my three Centers of Excellence. And when you come in, you have a holistic evaluation for you and your family about what's going on with you, your symptoms of Long COVID. We have onsite care for some of the more common things like an pulmonologist that can do pulmonary function tests, or cardiologist who can perform onsite echocardiography, uh, for patients, as you mentioned earlier that studies show are more likely to have consequences of COVID like that.

I'm happy to go in to more detail if that would be helpful.

CHAIRPERSON CABÁN: Yeah, you mentioned the $140 million for COVID Centers of Excellence, what is the budget for the AfterCare Program?

SENIOR VICE PRESIDENT LONG: So, the budget for the AfterCare Program is funded by OMB, and right now we are receiving the funding we need for, uh, again, the hundreds of AfterCare Navigators that we have through the three organizations that work with.

I defer to OMB to share more specifics about numbers.

CHAIRPERSON CABÁN: Okay, great.

And ,you know, I hear you describe these AfterCare Programs, the center, uhm, and so, I guess my question also is ,like, in your opinion, right, there is this infrastructure that is laid out presumably to tackle this very real health epidemic that are experiencing. Do you find that our current public health policy, like taking away mask mandates, stopping The Test & Trace, and all of these different things are counterproductive and kind of undercut the ability for this great infrastructure to have the kind of impact it needs to or to achieve the goal that these... that this infrastructure ultimately has.

SENIOR VICE PRESIDENT LONG: I will answer maybe the second part, and I will turn to Celia to answer the first part about some of the other public health measures like masks.

One of the things that makes me proud to be a New Yorker every day, is I remain your Executive Director of the New York City The Test & Trace Corps. We are stronger than we have ever been, and we have units now that can go around into our communities, 75% of the time in our Taskforce on Racial Inclusion & Equity neighborhoods. We offer you testing; if you test positive speak to a clinician, get Paxlovid, you walk away with it within 20 minutes. That is the type of thing that we want to do a lot more of in New York City -- to meet people where they are -- so that we can be able to treat New Yorkers with the tools that we have in our tool belt now.

So, The Test & Trace, I just wanted to say, uh, is very much still here for New York City, and will continue in New York to support New York City as long as COVID is a threat to any New Yorker. I'll let you... (CROSS-TALK)

DEPUTY COMMISSIONER QUINN: Yeah, and thank you. Uh, Chair Cabán, you mentioned in your opening

remarks that COVID is still here, it's still impacting New Yorkers on a daily basis. And to that end, The Health Department is still recommending a lot of preventive measures to help prevent people from becoming infected and to prevent severe illness and the consequences of that. So, we are still recommending that people wear masks in indoor settings, we definitely are encouraging people to be up to date on their vaccinations. And with a new bivalent vaccine, available just in the past few weeks, which is recommended for everyone 12 and older, we are doing a lot of community outreach through our Public Health Corps, through all of our work with providers, to make sure that people know that they, you know, should be getting this vaccine. We have a new media campaign release for that just starting this week. So, you know, I think all of these preventive measures are things that we are hoping to work with New Yorkers to make a part of their daily lives.

CHAIRPERSON CABÁN: And does The Health Department have recommendations around hybrid work? Right, I mean, out of all of the things that we know are unknown about Long COVID, we do know that the best

way to prevent Long COVID is to not contract COVID. And, again, for city workers, for example, we are seeing a real push to... that folks must be in person. Is there a recommendation or guidance around being able to work remotely?

DEPUTY COMMISSIONER QUINN: I think we have seen that people being vaccinated and following the preventive recommendations that I've already outlined, is effective at reducing transmission.

CHAIRPERSON CABÁN: And, so you don't have a recommendation around hybrid work polices or whether that would reduce the likelihood of contracting COVID and; therefore, Long COVID?

DEPUTY COMMISSIONER QUINN: We are still recommending that people wear masks in indoor settings, we recommend that people stay up to date on all of their vaccinations. And we are doing a lot of work to help people do that this fall.

CHAIRPERSON CABÁN: Okay.

And you also mentioned in your testimony, around I know that you hit on the hundreds of thousands of text messages that were sent out, and some of the patient resources and things like that, what is... you talked about some of the... the material

supports in terms of it -- what sounded like financial assistance, I'm assuming like low barrier grants? How much has been set aside for that? How much has spent up to this point? What is the process to access it?

SENIOR VICE PRESIDENT LONG: I can speak from the perspective of AfterCare, and then I will turn to Celia to see if she wants to add anything.

So, the way that we access financial resources is we use our AfterCare Navigators to navigate. And a lot of the resources that people need already exist, but people don't necessarily know how to get them. You know, an example that comes to mind often for me is the healthcare system is, uh, for Dr. Quinn and me, we really get it. We know to get almost anything in the healthcare system. I don't take for granted that my patients don't have the same understanding I do of how to navigate our healthcare system. The same way that I don't know how to navigate our financial systems as well as our AfterCare Navigators do, who are specifically trained to help people to get the resources that they need. So, things, uh, again like rent assistance, utilities assistance, a lot of these are programs that already exist in New

York City, but our job is to make so that we are able to bring all of these things to light to people -- whether it's healthcare you need or rental assistance. The reason we created AfterCare is that we didn't want to let any New Yorker suffer in silence at home without knowing that there was a place that they could go for whatever support that they would need. And that has really been our mantra and it's why AfterCare is so important to us.

CHAIRPERSON CABÁN: So, correct me if I am wrong, what you're... In terms of the financial assistance and other supports that you laid out in your testimony, that is already existing infrastructure, correct? Like, just do... Kind of being another sort of pass off point, it's sort of what we do in our Constituent Services Offices, right?

So, my question becomes, and I talked about this in my opening testimony, about the economic impact of Long COVID and people not being able to go to work as a result, the programs that we currently offer as a city, do they take into account Long COVID as a disability? Right? Like, what is the process there to make sure that, you know, we are feeding people into this infrastructure, but is it... Is it up to

date with the moment in time that we are in? Because when it, you know, when I listened to the testimony, what it sounded like to me was, like, oh, this sounds like specific, you know, again, low barrier grants for people experiencing Long COVID that are in an acute crisis and need some level of stabilization to stay in their homes, to put food on their tables, but that is not really what I am hearing.

So, I am also curious about if there are numbers and tracking of how many Long COVID patients are accessing and getting the financial assistance that they need in whatever area it is?

DEPUTY COMMISSIONER QUINN: Yeah, so, uh, you know, I can't speak to all of the different citywide programs that are available for people with a wide variety of needs. I think... Well, I think what you're opening remarks raised, is that because of Long COVID people are experiencing these needs. I think the H+H AfterCare Program has an excellent record of bringing people, connecting them by calling simple phone number, 212-COVID19, to get them access to a wide variety of supports that they might need as part of the, uhm, COVID care that they need.

And, in... (CROSS-TALK)

CHAIRPERSON CABÁN: Is there a data set available, are there numbers that you can provide us with?

SENIOR VICE PRESIDENT LONG: So, for the AfterCare Program, we do publish data that we put on our website. So, you can go to our The Test & Trace Website, which is one of the, uh, I learned this recently, there's a difference between a website and a web page, a web page on the Health + Hospitals website. And that has the data that we, you know, collect about the types of things people use from the AfterCare Program from the conversations. If you look at that and want to learn more, definitely send us an email and we'll be happy to [INAUDIBLE] ... (CROSS-TALK)

CHAIRPERSON CABÁN: And... And, that includes, and I'm sorry, because I can't pull it up right now... (CROSS-TALK)

SENIOR VICE PRESIDENT LONG: That's okay... (CROSS-TALK)

CHAIRPERSON CABÁN: But that... In terms of... That includes people who go through the AfterCare system and it would say, like, this many people got housing relief, this many people got, you know, money for their utilities or whatever. Does... Is that

the kind of data that is publicly available on the site?

SENIOR VICE PRESIDENT LONG: We break it up into more general buckets. But, for example, I can tell you that some of the more common things that we are able to help people with -- in terms of -- so, just to back up for a second, we have been able to complete, uh, referrals or in other words, to complete the connection to resources for more than 30,000 New Yorkers to date. So, 30,000... More than 30,000 New Yorkers, we have been able to connect to resources. Whether it's HRA, whether it's a Centers of Excellence for medical care, whether it's the Body Politic for community support.

Some examples, and then if you go to our website and take a look ,you know, be happy to talk more about it afterwards, but things that are more common is HRA is one of the more common things that people request. Utility assistance is fairly common, too. The most common is our Centers of Excellence. Which, I think makes sense, because a lot of the symptoms that, uh, constitute the, uhm, the condition we refer to Long COVID, are frankly scary for people. And a lot of the people that we're seeing, I see new

patients like the... this myself, there are people who are engaging with the healthcare system now, because they have a new symptom, like hair loss, that they are terrified by, they don't know what it means, and in New York City, we connect them to me as a doctor. In other cities, we don't have analogous, programs like this, but I am really proud that we do this proactive outreach and we have a clear place for people that are suffering from symptoms of Long COVID, or need financial support, or just need to be a part of a community support group. We give them a good, clear option in New York City just by calling 212-COVID19.

CHAIRPERSON CABÁN: Great, thank you.

A simple, but big question, is the funding for these programs sufficient given the current state of the pandemic and the number of New Yorkers suffering from Long COVID? And, also connected to that, how do you anticipate the 7.75% budget cuts over the next four years that The Mayor is requiring of DOHMH will affect the budgets and staffing?

DEPUTY COMMISSIONER QUINN: So, I will start. So, you know, I don't have specific budget numbers to share today. But, the work that The Health

Department is doing, and it's currently funded, encompasses a lot of different types of COVID-19 work, including the ongoing surveillance work around Long COVID that will help us understand not only who is currently impacted or might become impacted by Long COVID, but I think that will also help us understand what is the right level of utilization for the types of programs that H+H, for example, is using, and how to help design for those needs going forward. So, you know, we would never turn down additional funding to do more work.

CHAIRPERSON CABÁN: I would like for you all to have more funding.

And, then, finally, just... Has there been any interest in creating a citywide taskforce on Long COVID?

DEPUTY COMMISSIONER QUINN: So, currently, and I hope this is reflected in our testimony here today, there is a lot of collaboration between The Health Department and H+H, as well as multiple others city, state, and federal partners... (CROSS-TALK)

CHAIRPERSON CABÁN: Okay

DEPUTY COMMISSIONER QUINN: on this topic right now. We are frequently in conversations about new

findings as different scientific findings emerge. And I mentioned in the testimony that earlier this summer we held a symposium for both patients and providers about Long COVID with Health + Hospitals that was really designed to help providers understand how to recognize this, how to provide compassionate appropriate care, and how to refer people for additional ,you know, specialized care when they need it. So, those are the kinds of collaborations we're, you know, we are currently engaged in and expect to continue.

SENIOR VICE PRESIDENT LONG: And if I could just build on the symposium. I... To me the most powerful thing in the world is a patient's story. Nothing is more powerful than when my patients tell me every time I see them in clinic, and nothing is more powerful to me than hearing what patients have had to go through or those who are suffering in silence and have not been able to see a doctor yet. We led off of this symposium, and it's a... There's a public link for it, so you can view all of it later on. But, it was led off as it always should be, with patient stories about patients that have Long COVID now and what they have gone through and what they

need. And that's the right way to think about it. So, ,you know, the way that we are coming at this, is the symposium really informed ,you know, how we need to refine and keep our focus on Long COVID, but it starts with... it started with the stories of patients and that always needs to be our focus.

CHAIRPERSON CABÁN: Thank you. And I am going to pass it to Chair Moya.

CHAIRPERSON MOYA: Thank you, Chair Cabán. Just a couple of questions, uh, thank you both for your testimony here today.

I want to go back to a couple of things that we have kind of discussed in the past but are relevant to the topic of today's hearing.

Are the language barriers preventing the non-English speaking population from reporting the Long COVID symptoms and causing underreporting for Long COVID in immigrant communities?

DEPUTY COMMISSIONER QUINN: Uh, so, the figures that I mentioned from The Health Department's community health survey, just I'll give a little bit more detail about that survey so people can understand how we get that information.

So, this is an annual survey that The Health Department conducts, and it provides pretty robust data on the health of New Yorkers by neighborhood, by borough, and also citywide, and provides estimates on a broad range of chronic diseases and also behavioral health risk factors that really help us to plan for public health interventions but also many of our partners to help plan for interventions as well.

So, it's a cross-sectional survey, and there are appropriately 10,000 people who participate. It is all adults age 18 and older, from all five boroughs of New York City. These surveys are conducted by web, by phone, and pencil and paper depending on what people need. And the survey is conducted in English, Spanish, Russian, Chinese -- both Mandarin and Cantonese, Bengali, and Haitian Creole. So, then these are the data that we are analyzing to understand. And, people can visit our website to get information about the annual results of the community health survey. It can be found on the EpiQuery section of our website.

CHAIRPERSON MOYA: Thank you. And, have there, uh, been any impacts seen on fertility after COVID infections or with those suffering from Long COVID?

DEPUTY COMMISSIONER QUINN: So, I am not familiar with specific studies related to that. There may be some studies out there that address that issue. I expect that it is a little too early to know fully what the extent of the impact would be.

CHAIRPERSON MOYA: Okay. And does poverty in communities of color, uh, really create a deficit in Long COVID treatment similar to what caused the high mortality in those communities in the early days of the pandemic?

DEPUTY COMMISSIONER QUINN: So, I think, you know, access to care and access to resources needed for people to engage in healthcare is a very big problem. And, it is certainly something that has relevance to this conversation about Long COVID.

On the sort of epidemiology and assessment side, ,you know, I think there is a lot of national studies going on as well as our own health departments efforts to do surveillance for this condition here in New York City. I think some of those issues that you are raising around access to care will make it difficult for us to really understand what the impact is. But, those are things that -- I know in the

health department side -- we're working with academic partners to understand how to better study.

SENIOR VICE PRESIDENT LONG: And, if I could just add on there too, in terms of how we look at different communities. So, we center a three... As you know Centers of Excellence, we made the decision on where to put them based on where people were disproportionately impacted by COVID. And, then moving forward after that, one of the things about AfterCare that is so important to me as a primary care doctor, is this is a proactive way to reach out to people. We reached out to people in our Taskforce on Racial Inclusion & Equity Neighborhoods. We knew how to reach them, because we reached 89% of every single case in New York City through contacting tracing up until omicron. We reached you before nine out of 10 times, we can reach you again now to see how you're doing. And that gave us the ability to connect with people who often were suffering in silence at home, were confused by frightening symptoms, and didn't know how to access the support that they may have already qualified for. So, we wanted to be able to solve all of that, and that

really is the backbone of the AfterCare Program in terms of why it is so important to our city.

CHAIRPERSON MOYA: Alright, and does the hesitancy to receiving the vaccine in the past? Do communities of color are just [INAUDIBLE] like, uh, very, very skeptical of taking that. Has that had any impact on receiving treatment for Long COVID?

DEPUTY COMMISSIONER QUINN: Uh, so, you know, vaccine hesitancy is such a complex issue, on that we are continually working on in a variety of different ways. I think The Health Department's Public Health Corp has been very much engaged in a lot of communities of color, across all of the TRIE neighborhoods within New York City and elsewhere, to work on issues of vaccine hesitancy. We are also training these same community health workers to understand how to connect people to care for, you know, treatment of cute COVID, and also to recognize when to seek care for Long COVID.

CHAIRPERSON MOYA: Got it. Do you feel that the, uh, general population has a good understanding of the potential risk of COVID? And could we do more to inform COVID patients and those at risk of COVID about the risks of long term COVID as well? Like, I

am just trying to, like, see do you have a sense that they're getting... (CROSS-TALK)

DEPUTY COMMISSIONER QUINN: [INAUDIBLE]

CHAIRPERSON MOYA: It...

DEPUTY COMMISSIONER QUINN: Yeah. I think this is like, you know, this is the work of public health is to continually communicate to people about their current risks are. Especially as our understanding of what those risks are evolved... Like, with Long COVID, there is still a lot to be learned. I think there is certainly enough that we know to, you know, that preventing Long COVID is one reason to avoid being infected with COVID using those prevention measures that I have already described. So, you know, this is not something that we are seeing that we will stop doing. I think this is really the work of The Health Department to continue to educate people and help them understand how to avoid those health risks.

SENIOR VICE PRESIDENT LONG: And I would just add on to that, we are stronger together. So, if we all, everybody in this room, could know and tell five other people, call 212-COVID19 if you have symptoms that are scary to you -- if you don't know what's

going on, and you have had COVID in the past, uh, the city would be a healthier place.

CHAIRPERSON MOYA: Great, and then, uh, just this is going to be my last question, but what has been the economic impact of women taking off from work due to Long COVID? Since they seem to be impacted at a higher rate.

DEPUTY COMMISSIONER QUINN: I don't think... I don't have information about that; although, I think it's a very important question.

CHAIRPERSON MOYA: Alright, okay.

Well, thank you for that, I am going to turn it now over to Chair Cabán.

CHAIRPERSON CABÁN: Thank you, and I just have a couple of more questions for you. Uh, the first being, you know, you talked again a little bit about outreach, education, especially for New Yorkers -- patients -- right? But can you talk specifically about what H+H is doing to ensure that providers received adequate training that is grounded in several decades of expertise post viral chronic research and care, right, including on how to manage three of the most commonly... The common poor... poorly understood, yet treatable conditions arising

from Long COVID: ME, Mast Cell Activation Syndrome (MCAS), and then, forgive me, but, uhm, dysautonomia? You can help me out.

SENIOR VICE PRESIDENT LONG: You did great.

CHAIRPERSON CABÁN: Ah! Thank you, I appreciate that... (CROSS-TALK)

SENIOR VICE PRESIDENT LONG: [INAUDIBLE]... (CROSS-TALK)

CHAIRPERSON CABÁN: But, yeah, I mean, specifically, I want to hear more about like what we are doing to ensure that healthcare professionals received that adequate training on identifying and providing care for... for people with Long COVID and infection associated chronic illness?

SENIOR VICE PRESIDENT LONG: I would love to start, but as I... As I start, I am going to, you know, immediately point to Dr. Quinn and say, you know, this is a collaborative effort. How we train both our clinicians, but how Dr. Quinn trains the clinicians across New York City is something that we do together. We meet together, we meet together regularly about, uh, what clinicians, both in our system and outside of our system need, in order to take the best care of people. I'll give two examples

of what we do in our system, and then I will turn to Dr. Quinn.

One, is that we do... We have ways of bringing together our clinicians through usual leadership conferences, uh, and that is a way that we are able to put out the most recent evidence, because the evidence does change. One of the things that we see with our clinicians is the desire to see, as other symptoms or other, uh, facets of Long COVID are being discovered in the evidence, how can we inform them about it? How can we send them the most recent article on x, y, or z? So, we have regular, ongoing trainings for our clinicians in our system, but then also we built in to our electronic medical record, Epic, a special type of note that goes through just in case you forget something, all of what we know about Long COVID, so that when you're having the discussion with the patients, you see on the computer screen the reminder of exactly what to ask about. And we update that regularly as we learn more from the evidence as well.

DEPUTY COMMISSIONER QUINN: Thanks, and, yes, those are some really great examples of the kinds of best practices that we have tried to help all of the

healthcare systems put in to place. The Health Department has a number of ways to reach out to providers and educate them. In addition to the symposium that we did in June, we also sent out a Dear Colleague Letter that describes ,you know, many of the high level topics that were covered in the symposium, but also really reflects The Health Department's perspective on how important it is for physicians to listen, to take seriously complaints that might seem strange or not fit certain patterns, to ,you know, help people connect to the types of treatment or resources they need to manage their symptoms when they are experiencing them. So, those Dear Colleague Letters go out to tens of thousands of providers within New York City, and we have many ways of reaching them.

CHAIRPERSON CABÁN: And, then, my... My final question is related to this, but, you know, to compliment that, what is H+H doing or planning to do to help address implicit biases in healthcare professionals? So, you know, just to name a few, right? Like, women, Black women, particularly non-binary people, trans folks, gender nonconforming folks, and other queer folks that have historically,

uhm, gotten, you know, the short end of the stick when it comes to care?

SENIOR VICE PRESIDENT LONG: Yeah, and I think it's important to say that outright. Because at H+H, you know, it's woven in to the fabric of everything we do. We provide gender affirming care at H+H. We have six Pride Centers. At Metropolitan Hospital we, uhm, we do gender affirming surgery. So, you know, for us, it's woven in to the fabric of everything that we do. We have specific trainings on implicit bias, but more than the trainings, it's just part of how we deliver care. Everything we do, uhm, is focused on equity and focused on being gender affirming of all of our patients. And that is why H+H, uhm, is such a special place. Uhm, I'll...

(CROSS-TALK)

DEPUTY COMMISSIONER QUINN: Yeah, yeah, [INAUDIBLE] thanks, I was also going to jump in to add that ,you know, this is such a core part of what The Health Department -- how we see our role, and supporting providers to put these in to practice. And to that end, I just wanted highlight our LGBTQ+ Bill of Rights that The Health Department developed and that we use to promote across all of our work,

and that includes our efforts with neighborhood Health Action Centers with our Public Health Corp with providers in New York City.

CHAIRPERSON CABÁN: Okay, well, thank you, and thank you for being here, thank you for taking our questions. And, also thank you in advance for being responsive to our followups.

SENIOR VICE PRESIDENT LONG: Absolutely. Thank you for having us, and again, thank you for putting the spotlight on some critically important issues.

DEPUTY COMMISSIONER QUINN: Yes, agreed, thank you.

COMMITTEE COUNSEL: Okay, thank you so much. So, this finished the administration portion of the hearing. We will now be moving to public testimony. Please just gives us one moment. I will read the names of the panelists for the first panel for public testimony.

It will be Dr. Purpura, Namrata Pradhan, and I apologize in advance for any mispronunciations, Tatiana Bejar, Lisa Bernstein (sp?), Kenya Williams, and Elizabeth Martin.

Thank you to the administration, and it will be just one moment. We are just going to give people

who were named time to come up to the table. This will be a hybrid panel, so half in person, and half remote.

Okay, I am going to read the names, uh, and apologies, my name is Brenda McKinney, and I am a Senior Committee Counsel or Senior Legislative Counsel at the New York City Council. I work on The Committee on Women and Gender Equity. I am going to read the names of the members of this panel one more time. And we will go in order. Uh, so panelists will be muted -- who are testifying remotely -- until it is your turn, and then a box will pop up for you to click on.

The order of this panel will be Dr. Purpura, Namrata Pradhan from Adhikaar, Tatiana Bejar, Lisa Bernstein, Kenya Williams, and Elizabeth Martin, with the final two panelists in person.

So, at this point, we are ready to begin testimony. So, we will move to our first public panelists, which is Dr. Purpura. You may begin your testimony when the sergeant calls the clock, and you are on a three minute clock. Thank you.

SERGEANT AT ARMS: Starting time.

DR. PURPURA: 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 on the topic.

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 New York State and New York City 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-hand the impact of post-Ebola syndrome, which is strikingly similar to what we now know as 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 was doing 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 targeted 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 severe Long COVID. Our collaborators range from labs at Columbia, other academic centers across the nation, private biotechnology and pharmaceutical companies, as well as 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 in my infectious diseases clinic. I also work 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 severe 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 urge 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 for many and also resources and city-level to provide better care for New Yorkers. Thank you.

COMMITTEE COUNSEL: Okay, and just an update, because the first witness, Dr. Purpura, thank you, uh, has to leave at three o'clock, the chairs are going to ask questions of the first witness. Then we will return to the rest of the panel and save questions for the end of the panel.

CHAIRPERSON CABÁN: Great, thank you. Uh, first of all, thank you being with us. We really, really appreciate your testimony here today.

A couple of questions for you. I think ,you know, doctors who are not well versed in post-viral

illness may find that the normal battery of tests that they run on patients don't turn up results outside of acceptable parameters leading to believe that the symptoms are all in their patients' heads. Are there tests that you run that do show abnormal levels of physiological indicators?

DR. PURPURA: Thank you for that question. I think it really highlights one very important topic regarding clinical care with Long COVID, is that we have to listen to our patients and not necessarily just rely on laboratory testing despite that it goes against of lot how modern medicine is practiced. And I think we are learning how to respond to many of these more silent diseases through Long COVID.

So, specifically regarding what tests we order, so as a sub-specialist, I have access to more advanced testing than probably would typically be done by the more frontline primary care providers. So, by the time patients see me, they have already had routine screening, uh, looking for things that we would definitely want to rule out like diabetes, vitamin deficiencies, and other chronic illnesses. So, for my assessment, we do more advance immunologic testing. So, I am screening for autoimmune diseases,

as well getting, uh, a better sense of the functioning of the immune system. But, these tests can be more expensive, but as an infectious disease specialist, we can provide better justification for performing these tests. And, I will say that, uh, although rare, I have diagnosed several patients with autoimmune conditions that I believe have been worsened by COVID. And so I think a subset of patients are experiencing an unmasking of autoimmunity. We are also seeing that some patients are having just generalized immune dysfunction, and we can pick up signals in laboratory testing such as cytokine panels. And this is also being reflected in a lot of the basic science studies that have been coming out over the past few months that have defined hypothesis for different mechanisms of Long COVID including dysfunction T cells, as well as autoantibodies. So, in general, yes, there is more advanced testing that we can do. And, I think it... Once thing that we need to consider is how to offer these type of tests to patients who are either uninsured or that may not be available to them at the time.

CHAIRPERSON CABÁN: And, based on your, you know, your work, your experience, in your view do you think that employers should grant Long COVID patients reasonable accommodations?

DR. PURPURA: Absolutely. I think one important condition to highlight with Long COVID, is that there really is not one type of Long COVID. I look at Long COVID as many different Venn diagrams with a lot of overlap across the various types of symptoms. And these range from, as I mentioned before, from heart, the lungs, to the brain, uh, to the peripheral nerves. And they can all present with unique types of disability unfortunately. So, to... For example, patients with severe cognitive dysfunction, it is very important when managing chronic fatigue syndrome and brain fog that patients have the ability to limit their exertion. So, we call this pacing, and it's one of the tenets of treating chronic fatigue syndrome. And if employers aren't allowing patients to have this type of time to limit themselves so that they don't cause relapses or worsening of their symptoms, it can be detrimental to them. And the same thing goes to jobs that require more physical exertion, and the patients are having chronic shortness of breath

or have chronic cardiac conditions, or even weakness due to peripheral neuropathy, employers definitely need to take this into consideration. And, again, as I mentioned, uh, I write a lot of these letters, and I think it is a very important consideration.

CHAIRPERSON CABÁN: Thank you. Uh, and I am just going ask you two quick last questions, I know that you are under a time constraint. So, again, I am deeply grateful that you are here with us today.

But, you know, what can DOHMH and H+H do in order to ensure that providers are well educated about Long COVID? And, then, ,you know, with your experience with working with patients, what supports and resources do they need that they aren't currently getting?

DR. PURPURA: That is such a fantastic question. You know, I am very happy that both the state and the city have taken much more initiative in the past 12 months. I think both the symposiums are excellent examples of that. I was also assisting with the Dear Colleague Letter that was described earlier. I think all of these efforts are wonderful, and they need to target every level of the medical and public health system. So, as of now, this still feels like a lot

of Long COVID care is coming out of the academic centers and falling on to sub-specialist. And unfortunately, the wait time to see many of us two to three months if not longer. So, I think in terms of how we can immediately improve access to care, it would, you know, typically mean providing better education to healthcare providers at all levels. And I think taking it out of the sub-specialties and putting it into primary care would be an excellent first step. So, I think the Dear Colleague Letter was a, you know, a first initiative that was done, but I think clearly there can be a lot more done to provide education to all of the providers across the city. So, I think that is an initial step that would be very beneficial.

And, just in terms of providing care to patients, you know, something that I am trying to work on, is how do we provide recourses and education prior to when a patient can actually be seen by a healthcare provider. And even if it takes several weeks to see a provider, you know, there are things that we recommend at our first visits that do not necessarily require an in person visit or even a phone call. A lot of can be done through dissemination of

information, through either online resources or pamphlets. And I think having... By giving people who may have concern for Long COVID, these type of resources, they can start to educate themselves and already make lifestyle and dietary changes that could immediately impact them.

So, I think overall there needs to be more of an emphasis towards doing things to immediately provide information and care to patients. And this could be both at the patient level, but also at the provider and public health level.

CHAIRPERSON CABÁN: Thank you.

COMMITTEE COUNSEL: Chair Moya, you don't have any questions?

Okay, thank you very much. We will now move to our next panelist, thank you, Doctor.

And we will continue with this panel. Just one moment, please.

Alright, so our next witness will be Namrata Pradhan (*from) Adhikaar (sic). You may begin your testimony when the sergeant calls the clock.

SERGEANT AT ARMS: Starting time.

NAMRATA PRADHAN: Hi, good afternoon, I am Namrata Pradhan, I am an Organizer for Adhikaar. So, our worker leader, Rukmani, is testifying today.

RUKAMANI BHAATTARAI: Hi, Namaste, Namaste, everyone. My name is Rukamani Bhaattarai, I am an active member of the Adhikaar and a leader... Sorry, a leader [INAUDIBLE] Adhikaar [INAUDIBLE] training, and have been working as a domestic worker in NYC since 2017. I am speaking on behalf of the hundreds and thousands of domestic workers in New York City and 1,800 other Nepali Speaking domestic workers, members of Adhikaar.

In the 2020, during the pandemic, I lost my job, and I did not have any income source, and it impacted my mental and physical health. I did not have any medication in my apartment and was unable to get the medication [INAUDIBLE] crying pain. This [INAUDIBLE] I did not have the option as the doctor's office [INAUDIBLE] wasn't open then. When I Googled it myself, I found out that it was a frozen shoulder. I started doing the exercises and somehow finally found some relief. When I felt a little better, I started looking for a job, but it was so hard. I interviewed for at least 16 or 17 different places, but nowhere

did they offer what I knew was the minimum wage and my basic right as a domestic worker in New York City. I also experienced a lot of discrimination during this process, which made the experience much harder. This struggle added to my mental, emotional, and physical pain. And it made me so sad, so sad to know that as a domestic worker, we were forced to have to accept jobs that did not provide our basic rights just because we needed a job. This is not only my story, this is the painful story of thousands of my domestic worker sisters. However, we are called essential workers, but we never get the same benefits as the other essential workers.

Today, I am testifying for The Committee on Women and Gender Equity and the Subcommittee on COVID Recovery and Resiliency to ask you to support The Domestic Worker and Employer Empowerment Initiative. We need this initiative to build up our service [INAUDIBLE] service education and leadership development for other domestic workers like me. And we need to ensure that employers are being educated to understand and [INAUDIBLE] follow their responsibilities. With the [INAUDIBLE]... (CROSS-TALK)

CHAIRPERSON MOYA: Thank you. Thank you so much for your testimony... Thank you so much for your testimony today, thank you.

RUKAMANI BHAATTARAI: [INAUDIBLE] work [INAUDIBLE]

CHAIRPERSON MOYA: Thank you so much for your testimony today, thank you.

RUKAMANI BHAATTARAI: Thank you, thank you very much, Namaste.

COMMITTEE COUNSEL: Thank you so much for your testimony.

We will now move to the two live witnesses... Oh, apologies, the next witness will be Lisa Bernstein. If you are ready to testify, you may be begin when the sergeant calls the clock.

LISA BERNSTEIN: Okay, thank you... (CROSS-TALK)

SERGEANT AT ARMS: Starting time... Starting time.

LISA BERNSTEIN: Hello, my name is Lisa Bernstein, and I am honored to be here as a member of Hand in Hand: The Domestic Employers Network, a national network of employers of nannies, house cleaners, home attendants, and family caregivers, who works with domestic worker organizations to transform the care sector to one that is fair and equitable.

Hand in Hand is a member of the NYC Coalition for Domestic Work, along with the National Domestic Workers Alliance, The Domestic Employers Network, Adhikaar, and Carroll Gardens Association.

Since the day my daughter was born, 27 years ago, I have employed domestic workers. In fact, without Glendora and Philippa (sp?), the amazing nannies who cared for my children, or Carmina (sp?), who now cares for my mother-in-law, I am not exaggerating, without these women, I would not have been able to do my work or support my family in New York City for the last 27 years.

But, of course, all of us, especially mothers, know that caregiving is at the very heart and soul of our lives, our humanity, and our economy. Every day, it is the caregivers who are the true essential workers of New York.

During the first year of COVID, my mother-in-law's Alzheimer symptoms worsened and she needed round the clock care. I wanted to know I could do the right thing, and with the COVID, the safe thing for our family, for my mother-in-law, and of course for her new caregiver. But, not surprisingly, these essential workers were, and still are, forgotten at

the federal, state, and New York City level. There was no guidance or support for employers of domestic workers. Once again, our systems, our culture, and our city forgot to value the work that is most valuable. It was a wakeup call for me, and it's why I joined Hand in Hand: The Domestic Employers Network.

The domestic workers of New York City were desperate when COVID locked the city down. Many of them lost their jobs. They had no safety net and no protection. And they didn't even received simple recognition of the truly essential nature of their work.

Some employers who worked from home fired their nanny or housekeeper with no notice; others made insane demands. But just as many employers paid whatever they could do keep their family and their employees family safe during early COVID -- understanding that the salary they paid was keeping another family fed.

Domestic work cannot be done remotely. It is often emotion as well as physical work. Domestic workers wake up every morning to provide care to others, yet cannot stay home to care for themselves

of their families no matter how sick they may feel. Many cannot afford to take the time off needed to recover from COVID, and, so, ironically, they are then very much at risk for Long COVID.

The ability to rest, recover, and still be able to eat and pay the rent, this is the very definition of a social determinate of health.

COVID and Long COVID continue. So, please don't once again forget domestic workers. Employers who want to do the right thing need the city's leadership on the continuing COVID and Long COVID crisis. This is just one of the reasons why I proudly support The Domestic Worker and Employer Empowerment... (CROSS-TALK)

SERGEANT AT ARMS: Time expired.

LISA BERNSTEIN: Initiative, sorry.

CHAIRPERSON CABÁN: Well, thank you.

COMMITTEE COUNSEL: Okay, thank you so much for your testimony.

And just a reminder that we accept... Uh, The Council accepts written testimony up to 72 hours after the start of the hearing. You can email written testimony to testimony@council.nyc.gov. That written testimony does not have a limit. So, please

feel free to contact staff if you have questions and email written testimony.

We will now move to the next witness on this panel. There are two more witnesses. The next witness is in person, Kenya Williams from the NYC Coalition for Domestic Work.

KENYA WILLIAMS: Good afternoon, thank you, Chair, and council members on the committee, for offering me time to speak this afternoon.

My name is Kenya Williams, I am a domestic worker and a member of Carroll Gardens Association. We along with the National Domestic Workers Alliance, Adhikaar, and Hand in Hand, comprise the NYC Coalition for Domestic Work. Together, we represent 30,000 domestic workers and employees across New York City.

I am here this afternoon to talk about the impact of COVID-19 on domestic workers like myself. When the pandemic started over two years ago now, I was working a building in a Brooklyn; a nonprofit organization came in to the building donating face masks and gloves to the tenants in this building. I proceeded to ask if I could have a few boxes of the masks and gloves for my nonprofit organization, which

I am member, The Carroll Gardens Nannies Association. I was told, no, because they were only giving them out to essential workers. The building that I worked in had many tenants, but not even half of them were essential workers, but yet they qualified to receive this package while I didn't.

And then the shutdown happened. I realized as a domestic worker that I didn't qualify for a lot of things that were being put into place. We as domestic workers were left out of the equation, yet it was essential for us to show up for work every day so that others could go to work or continue working at home while we cared for their children.

So, I am standing in front of you today asking you to help me prove that we are essential workers and we must be included in your equation.

Our coalition launched the Domestic Worker and Employer Empowerment Initiative, a Council initiative for FY23, which would provide much needed funding to support outreach, education, and enforcement support to domestic workers across New York City.

We hope you vote for our initiative which is on the agenda for next week's general council meeting.

Thank you for your time, Chair, and committee members, we look forward to working with you to build a city where domestic workers are valued and dignified. Thank you.

COMMITTEE COUNSEL: Thank you so much for your testimony.

The last person on this panel will be Elizabeth Martin, who is also testifying in person. You may begin, thank you.

ELIZABETH MARTIN: Thank you. My name is Elizabeth, I live in Brooklyn and work as a Product Manager at Salesforce. I am here to voice my experience living with Long COVID following an initial infection that began on February 29, 2020.

I would like to begin by giving a sense of what my life was like prior to COVID. Prior to getting COVID, I traveled to 19 countries across five continents, I organized multi-day and multi-week bike trips, and I volunteered for nonprofits in the Dominican Republic and at the US/Mexico border. Closer to home, I volunteered and taught software development to New York City high schoolers out of the Salesforce office after work. I lifted weights, did palates, 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 limit my walking to eight or nine minutes between any two points. If a distance is 10 minutes of longer, I will ride an electric scooter -- which was purchased specifically for this purpose -- or take an Uber or a 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 myalgic encephalomyelitis (chronic fatigue syndrome). I spend an inordinate amount of time managing my diet, supplements, medical appointments, and place extreme limits on how much energy I extend both physically and mentally just to maintain a very fragile baseline. Going beyond these limits, which are far lower than any able-bodied person might expect, can result in sleep apnea, neuropathy, fibromyalgia-like pain, headaches, brain fog, and debilitating fatigue. There are individuals who I know personally who have pushed themselves beyond these limits and are now bedbound as a result.

There are two reasons I am still able to work fulltime. The first is that my job is 100% remote and extremely flexible, my team is supportive, and I can take a break whenever I need to. The second is the full and unwavering support of my husband who does the vast majority of our cooking, cleaning, shopping, and taking care of our dog in order to reduce the burden on myself. Without these two lines of support, despite a Bachelors Degree in Chemical Engineering from Columbia University and a Masters in Management Science from Stanford, I can very 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 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 them did not accept insurance, many of them are out of network. After what is covered by insurance, my health care related expenses exceed thousands of dollars annually.

There are no areas of policy that I am aware of under The City Council's jurisdiction, which affect

me personally, I only hope to share my experience in case it might help others. Thank you.

CHAIRPERSON CABÁN: Thank you. I just want to thank everybody for your testimony and for sharing your lived experiences. It's deeply appreciated. I also want to share that my mother is a retired domestic worker who also struggles with chronic illness. So, this is all deeply personal to me as well.

I do have a followup. I know, Miss Williams, you mentioned legislation that you would like to see the council support, but for any of the other folks on the panel, you know, what are... Based on your experiences, what you're finding I, your needs as directly impacted folks, or members of organizations that are doing advocacy on this front, you know, what... What would you like to see New Yorker Council do to support people living with Long COVID?

KENYA WILLIAMS: We would like support in educating domestic workers as well as the employees, so that they know that we need to work together. We feel if the employees know, it could help them put things in to place just in case we do get sick and we need disability -- that the funding is there for us

to do these things so we can recover. We truly are essential workers, because we have to show up so that other essential workers can go to work. So, we should be in that category as well.

CHAIRPERSON CABÁN: Absolutely. Thank you. Oh, and I think Miss Bernstein has their... their hand up, and then we'll come back over here.

LISA BERNSTEIN: Yes, thank you. I just want to... I had gotten cut off, but one... The Domestic Worker and Employer Empowerment Council Initiative that is on the agenda for next week's General Council Meeting...

CHAIRPERSON CABÁN: Right.

LISA BERNSTEIN: For funding for educational programs for Fiscal Year 2023, I hope people will vote on that, because a lot of that is about building educational information about the needs of domestic workers with and for domestic employers. Oh, I'm sorry [INAUDIBLE] thank you.

CHAIRPERSON CABÁN: Thank you.

COMMITTEE COUNSEL: And if anyone else on this panel... Apologies, just to flag, uhm, if you use the Zoom Raise Hand Function, if you'd like to speak just because we have to unmute.

CHAIRPERSON CABÁN: Go ahead.

ELIZABETH MARTIN: Uh, I don't have any specific areas of policy that would impact myself that they mentioned that I am aware of, but I worry most about members of our community who don't have the resources to come and testify today -- members who may not be aware of the resources that were discussed earlier. I am a member of the Body Politic community that he mentioned. I have probably seen every post in the New York City community since the summer of 2020. I have never seen anything about financial support for New York City residents. So, I don't know how individuals are getting that information. I also hope that The City Council is aware of the requirements for disability that people with Long COVID have -- and disability protections and maintaining income continuity and stability so that they don't have to leave their places of residence. In addition to that, I have seen reports of individuals who were required to go into the office, who worked for the City specifically, I don't know if that's still happening, but I know that that would be a detriment to myself if I had to do so with this illness.

CHAIRPERSON CABÁN: Thank you. And, I know, certainly, I think it was at a recent hearing we had on retaining municipal workers in the City, and, uhm, continue to be critical of the current administration's position on demanding full in person work for basically all folks. So, I hear that loud and clear, and I definitely would like to be a partner in that work.

Thank you again, all of you, for your testimony and also for answering my questions.

COMMITTEE COUNSEL: Thank you so much. This concludes panel one.

We will now be moving to panel two. I will read the names of all of the panelists in order and then will call you.

Uh, the public panel two is Dr. Putrino, Ed Yong, JD Davids, Kimberleigh Smith, Juan Pinzon, and Mae Smith.

So, again, public panel two is Dr. Putrino, Ed Yong, JD Davids, Kimberleigh Smith, Juan Pinzon, and Mae Smith.

Okay, so, we are now ready for public two. Dr. Putrino, if you are ready to testify, you may begin when the sergeant calls the clock.

SERGEANT AT ARMS: Starting time.

DR. PUTRINO: Hello, everyone, my name is David Putrino, I am the Director of Rehabilitation Innovation for Mount Sinai Health System.

My team has been working with Long COVID patients since May of 2020 when we first noticed that about 15% of the thousands of New Yorkers that we were monitoring acutely for COVID started to develop chronic symptoms.

As we have started to care for thousands of people with Long COVID, we have begun to publish findings in peer reviewed journals about the common presentations of Long COVID and symptom severity associated with Long COVID. There are a few things that I want to share with on that. The first is that around 70% of our [INAUDIBLE] are female who experience significant symptom worsening associated with hormonal cycling. And, so this is definitely a condition that significantly and disproportionately disables women, and that is something that we should be aware of. Fifty percent of our patients who come to our clinic have experienced a change in their employment status as a result of the severity of their Long COVID symptoms. Thirty percent of that

group are now unemployed as a result of their Long COVID symptoms. And, then finally, over 60% of our patients were experiencing measurable cognitive impairment on a scale that we call the neurological quality of life that we typically use to measure cognitive impairment in people with traumatic brain injury and stokes. So highly significant cognitive [INAUDIBLE]. So, that is what we have noticed in the past.

As we move forward into our current research and work and the gaps that we see in New York State, I would say that one of the major problems that we see is that many Long COVID clinic across the state are still turning patients away if they don't have a positive pcr or antibody test. This is against CDC policy and against CDC diagnostic criteria. So, we desperately need New York State to enforce CDC policies [INAUDIBLE] anyone who meets diagnostic criteria can be seen by a Long COVID clinic. Otherwise, putting this parameters and blocking people without a pcr test or an antibody test will significantly worsen existing disparities in health for people with Long COVID.

We also just simply need to set up free clinics for people with Long COVID. I will here and now volunteer myself as someone who is willing to educate clinicians who are willing to staff Long COVID clinics -- free Long COVID clinics, because currently free clinic around the City do not have doctors that are well educated in Long COVID. So, we need that urgently.

Similarly we are seeing that many insurers are denying claims for necessary care. The argument we receive is that necessary care for Long COVID is poorly defined. And so we end up in this dangerous scenario where insurers actually get to dictate what is necessary care as opposed to clinicians. We should as a state be developing... (CROSS-TALK)

SERGEANT AT ARMS: Time expired.

DR. PUTRINO: policy... Oh, pardon me?

CHAIRPERSON CABÁN: Please do finish your remarks, thank you.

DR. PUTRINO: We need to be developing policy to guide and enforce standards for necessary care. And the same for granting short and long-term disability [INAUDIBLE].

CHAIRPERSON CABÁN: Thank you.

DR. PUTRINO: I have... Okay.

COMMITTEE COUNSEL: So, just to... And, just a logistics update, as with the first panel, Dr. Purtino, uh, has a time constraint. A number of physicians who are testifying today are also seeing patients. So, we are going to take questions and answers after several witnesses, but normally, uh, still after the panel for most witnesses as well.

So, Chair Cabán?

CHAIRPERSON CABÁN: Yes, Dr. Putrino, sorry, it sounded like you were going to make an additional point before your time expired. And, so in recognition of your expertise in the field, I just want to give you an opportunity now to round out your earlier remark, and then I have a followup question for you.

DR. PUTRINO: Well, thank you so much.

I was just going to say that finally, uh, Dr. Akiko Iwasaki and I, a collaboration between Yale and Mount Sinai, recently published some work showing that we can identify people with Long COVID from a control group using blood biomarkers with 96% accuracy. But this are inaccessible to blood tests for most physicians, and certainly they are not

covered by insurance. So, I think that is something that we need to work toward as a group a rapid fire technology translation pipeline. This is a public health crisis, and we are in the midst of a mass disabling event, which is worsening every, single day. New York State has the tools to make a difference in this fight. So, I think we just need rapid action to translate some of these scientific findings into actionable treatments and assessments for Long COVID. And, thank you for the extra time.

CHAIRPERSON CABÁN: Thank you. I just... I mean so many things that you said have me kind of a little bit floored, like hearing ,you know, for the women that you have seen, 50% change in employment, and of those 30% experiencing then unemployment.

But, I want to make sure I got something right, because I want to follow up with the Admin on it. Can you touch on this again? You said that in terms of the gaps of the City's infrastructure for providing care and resources for Long COVID patients that turning away people if they are not testing positive on PCR testing. So, what is your understanding of the policy? Who is getting turned away and why?

DR. PUTRINO: Yes, thanks for asking for clarity on that.

So, many Long COVID patients, by the time they reach our clinic, they will experience at many Long COVID clinics, they are told we cannot see you as a Long COVID patient unless you have a documented medical history of acute COVID infection such as a positive PCR test or a positive antibody test in your medical history that is a medical confirmation of COVID.

Now, what I find frustrating about that is that our CDC diagnostic criteria for Long COVID does not require objective medical documentation of an acute COVID infection. Simply the suspicion of an acute COVID infection, based on symptoms that a patient experienced prior to developing Long COVID symptoms. To state that more plainly, if you got sick with flu like symptoms, and then went on to develop Long COVID symptoms, that should be enough for a physician to say, this sounds a lot like Long COVID, we are going to give you a Long COVID diagnosis. And that is not me saying that, that's the CDC and their guidelines.

CHAIRPERSON CABÁN: Thank you. Do you have any questions for the doctor? Okay.

Thanks so much.

COMMITTEE COUNSEL: Thank you, Doctor.

We will now move to Ed Yong... (CROSS-TALK)

DR. PUTRINO: Thank you.

CHAIRPERSON CABÁN: The next witness on this panel. You may begin when the sergeant calls the clock.

SERGEANT AT ARMS: Starting time.

ED YONG: Thank you. I am a staff writer at The Atlantic, and I have been reporting on the COVID pandemic since almost its beginning.

I first reported on Long COVID in June 2020 when the official word was that COVID would either be severe enough to land people in an ICU, or so mild that people would recover within weeks.

But, even then, that wasn't true. Countless people were already stuck in the space between death and recovery, rapt with debilitating and persistent symptoms, but waxed and waned erratically, and that affected seemingly every organ system in the body.

Two years on, Long COVID is more widely know, largely due to the efforts of Long haulers themselves. But several aspects of the condition are frustratingly true now as they were then.

First, while some people gradually get better, others do not. Some of the people I interviewed more than 900 days ago, are still sick.

Second, COVID Long haulers are disproportionality women, as you have already heard.

The third, almost all of them have experienced some form of societal dismissal. They have been told by friends, family members, employers, colleagues -- and worst of all, by doctors and healthcare workers that their debilitating symptoms are in their heads or simply the result of anxiety or depression. People have been given diagnoses as ridiculous as ear wax buildup or middle age.

And fourth, their symptoms are very real. Consider the effect of just brain fog, one of the most common symptoms. This is specifically a problem with executive function, the set of mental abilities that includes focusing attention, blocking out distractions, and holding information in mind. These skills are so foundational that when they crumble, much of a person's cognitive edifice also collapses. Anything involving concentration, multi-tasking and planning, which is basically almost everything important that we do, becomes arduously... absurdly

arduous. Many people with brain fog struggle to drive, to read, to buy food or make meals. Memory takes a hit, and people lose connections to their pasts and to their identities.

In these traits, Long COVID has much in common with other complex chronic illnesses, including but not limited to, fibromyalgia, dysautonomia, Ehlers-Danlos syndrome, and myalgic encephalomyelitis -- also known as chronic fatigue syndrome or ME/CFS.

These illnesses travel in packs. They overlap significantly in their symptoms, and many cases of Long COVID are effectively ME/CFS by another name. They disproportionality effect women. And because they disproportionality effect women, they are tragically neglected. There's no money spent on studying them. The NIH spends less on any ME/CFS every year than any other disease in its portfolio relative to societal burden. Few medical schools teach these illnesses so few doctors learn about them. And since the medical profession has a long history of labeling women as "emotional" or "hysterical" and psychologizing their pain, when people with these illnesses seek medical care, they are often dismissed or gaslit.

On average, it takes a women with... (CROSS-TALK)

SERGEANT AT ARMS: Time.

ED YONG: with Ehlers-Danlos syndrome 16 years to get a diagnosis, a man needs only four.

As my dear friend, author and ME/CFS advocate, Sarah Ramey, wrote in her memoir, The Lady's Handbook for Her Mysterious Illness, "The illness itself is horrible and ravaging, but being told you've made it up, over and over again, is by far the worst of it."

I have now written five stories about Long COVID and sister illnesses like ME/CFS, with the sixth to be published next week. Every, single time, I get hundreds of messages from people who either have these conditions or care for those who do. I wish I could even begin to convey to you the cumulative anguish in these messages. Many say that these pieces mark the first time that they have had the merest flicker of validation and acceptance.

I want those of you with the privilege of good health to really contemplate what that means -- what it would be like to have your life contract to an unrecognizable shell, while those you turn to for care and support tell you that nothing is wrong. I

want you to think about living through that state of misunderstood pain for months, years, decades, or perhaps an entire lifetime. I want you to amplify that image millions of times over, and sit with the collective weight of all those disrupted careers, disintegrated dreams, and lost joys.

This is a medical crisis and a moral travesty -- one that long precedes COVID, but has been greatly exacerbated by it. Women make up the majority of the essential workforce that America relied upon throughout the pandemic. Many of them, especially immigrants and people of color, worked in jobs that significantly exposed them to infection -- nurses, grocery workers, nursing home staff, and many more. As sociologist, Jessica Calarco, once said, "Other countries have social safety nets, the US has women." And, in turn for their labor, much of the country then turned its back on those who were disabled by infection. This surely cannot stand. We need more research in to Long COVID, ME/CFS, and their related illnesses. More doctors need to learn about these conditions, especially from the few clinicians who actually understand how to diagnose and treat them. Many are still prescribing potentially harmful

treatments, like exercise therapy, which are unsuitable for people whose illnesses can become substantially worse with even mild exertion.

Long haulers also need social support since many can no longer work. But, for all of their medical woes, the Long COVID community is neither passive nor powerless. Over the last two years, I have seen Long haulers, again, mostly women, push the world's mighty health organizations, the WHO, the NIH, the CDC, and many more, to officially recognize their illness by seeing groups like the patient that research collaborative study Long COVID at times when few others would.

I have seen advocates for diseases like ME/CFS reach out to new Long haulers in solidarity and support despite the fiscal cost to them of doing so. Their efforts have been, and continue to be, remarkable and heroic. But, we should not tolerate a world in which some of the sickest people, who have a condition that saps their energy, are left alone to fight for their own rights. We should ask less of them, and more of ourselves.

Thank you.

CHAIRPERSON CABÁN: Thank you, *so* much for your testimony. In fact, it was so thorough that, uh, the questions I anticipated asking you, you have already covered. But, thank you. Thank you for the work you're doing. Thank you for your continued reporting on this. And, thank you for the care and thoughtfulness with which you are taking in and carrying other people's stories. So, thank you, again.

ED YONG: You're welcome, take care.

COMMITTEE COUNSEL: Okay, we will now move to the next member of the panel, uh, Mr. JD Davids, you may begin your testimony when ready.

SERGEANT AT ARMS: Starting time.

JD DAVIDS: Thank you. Thank you, I am JD Davids, I live in Brooklyn, New York, and I am the co-founder of The Network for Long COVID Justice, a project with 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, diagnosis, care, treatment and support for trans 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.

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, as: The Census Bureau survey 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. 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.

I invite you to imagine facing all you have already heard today of the anguish and horrors of Long COVID laid upon a life of ongoing trauma, violence, and marginalization. Trans people, especially Black, Brown, and indigenous trans people are also likely to have comorbidities that increase risk of both COVID-19 harms as well as Long COVID.

In a 2019-2020 study on HIV Prevalence among Transgender Women in 7 US Cities, 42% of women interviewed were living with HIV, which includes 62% of the Black/African American women and 35% of Latina women. Not only that, people living with HIV are four times as likely to have Long COVID than those who are HIV negative.

With limited time, I have written three recommendations in my submitted written testimony. But, I will stress the first one:

Train and employ trans people as Long COVID-focused community health workers, doulas, and home health aides to educate, 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... (CROSS-TALK)

SERGEANT AT ARMS: Time expired.

JD DAVIDS: 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.

We need a dedicated trans led, trans accountable community education process to help our community learn about Long COVID, get diagnosis, and get the support and treatment we need. Thank you.

CHAIRPERSON CABÁN: Thank you so much.

COMMITTEE COUNSEL: Thank you.

The next witness will be Kimberleigh Smith from Callen-Lorde Community Health Center. You may begin your testimony when the sergeant calls the time.

SERGEANT AT ARMS: Starting time.

KIMBERLEIGH SMITH: Good Afternoon. Thank you, Chairs Cabán and Moya for the opportunity to testify this afternoon.

I am Kimberleigh Smith, and I am from Callen-Lorde Community Health Center, but this afternoon I am going to be 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.

"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 Long COVID 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 New York City law. Several of those diagnosed with Long COVID 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 Long COVID 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 Long COVID 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 a sustained and increased educational outreach campaign on the symptoms of Long COVID, 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 Long COVID 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 New York City.

I thank you again for this opportunity. We will submit a slightly lengthier version of these comments for the record."

Thank you.

CHAIRPERSON CABÁN: Thank you.

COMMITTEE COUNSEL: Thank you so much for your testimony.

The next witness will be Juan Pinzon. You may begin your testimony when the sergeant calls the clock.

SERGEANT AT ARMS: Starting time.

JUAN PINZON: Good afternoon, and thank you for the opportunity to testify, Chair Cabán and Chair Moya. My name is Juan Pinzon, I am the Director of Government Engagement at the Community Service Society of New York.

CSS health programs help approximately 130,000 New Yorkers access healthcare [INAUDIBLE] care every year. We do these through our [INAUDIBLE] and in

partnership with over community based organizations throughout the city and state.

Today I would like to talk about the challenges experienced by clients when accessing and paying for care related to Long COVID. Many of our Long COVID clients come through the New York City Managed Care Consumer Assistance Program, also known as MCCAP, which is a consumer assistance program that helps people resolve health insurance problems and access care -- especially for those who are uninsured.

Long COVID exposes patients to high costs both financially [INAUDIBLE] required to manage issues such as prior authorizations, insurance denials, and confusing medical bills. These barriers disproportionality affect women, because of the likelihood of long term COVID-19 complications associated with gender. And as we have heard for other panelists today, women also experienced greater economic and social stressors during the pandemic, which is contributing to a disproportionate mental health burden.

During the pandemic, MCCAP has provided much needed advocacy assistance to these patients who have struggled to secure coverage, care, and social

services. We have served over 8,000 people, most who are women, people of color, and speak a foreign language. The program operates through a "hub-and-spokes" model in which CSS acts as the hub with a free helpline and technical assistance role, while 12 CBOs serve as the spokes providing in person services in 15 languages at multiple locations across all of the five boroughs.

MCCAP's community based approach means that clients received culturally and linguistically competent services which can make a big difference as to where they receive the care that they need. For example, we have recently helped an 80-year-old woman experiencing long term respiratory and mental health complications as a result of COVID. Through the South Asian Council for Social Services, a MCCAP CBO, we have helped this client get her COVID vaccines and booster shots, organized care at rehab facilities, and connected her to providers who understand her physical and mental health struggles.

New York City's residents need programs like MCCAP more than ever, because navigating health insurance is only getting more difficult. And when you add on top of that, the complexity of the health

and economic issues created by Long COVID, this creates even more challenges for patients.

Thank you for the opportunity to submit this testimony today.

CHAIRPERSON CABÁN: Thank you.

COMMITTEE COUNSEL: Thank you so much. And, just a quick update, we will now go to Mae Smith, but there will be one more panelists on this panel, Dr. Anthony Komaroff. So, we will go to Mae Smith, and then Dr. Komaroff to conclude the panel.

So, Mae Smith, you may begin your testimony when the sergeant calls the clock, thank you.

SERGEANT AT ARMS: Starting time.

MAE SMITH: Good afternoon, and thank you so much for hosting this important hearing. I am submitting a more detailed version of this testimony in written form, but today I want to tell you a bit about my experience as a City worker with Long COVID.

Several months after my initial quote, unquote, "mild" case of COVID in April 2020, my health descended rapidly. Even after the smallest physical exertion, my body and mind were completely wrecked. If I was in a Zoom meeting for more than 20 minutes, I couldn't focus anymore - my brain just stopped

working. I couldn't think clearly, I couldn't exercise, I could hardly walk upstairs. 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 companies, 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, Body Politic, I learned that there was only a tiny number

of physicians in the greater New York area who specialized in ME/CFS, myalgic encephalomyelitis, and other post-viral illnesses like Long COVID. I called one of the main ones, Dr. Susan Levine, and was lucky to get in. I believe she now has a waitlist nearly a year long, so the vast majority other Long COVID patients are not so fortunate.

Having treated post-viral illness for decades, Dr. Levine 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 (Epstein–Barr virus), 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... (CROSS-TALK)

SERGEANT AT ARMS: Time expired.

MAE SMITH: I worked for... (CROSS-TALK)

CHAIRPERSON CABÁN: Go ahead, Mae, you can finish your remarks.

MAE SMITH: Thank you.

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.

Thank you very much for the opportunity to testify.

CHAIRPERSON CABÁN: Thank you for your testimony.

COMMITTEE COUNSEL: Thank you.

We will now move to the final witness on this panel. Dr. Komaroff, you may begin your testimony when ready, thank you.

DR. KOMAROFF: Thank you... (CROSS-TALK)

SERGEANT AT ARMS: Starting time.

DR. KOMAROFF: Can you enable, share screen?

COMMITTEE COUNSEL: We can see and hear you, Doctor.

DR. KOMAROFF: Okay. Can you see slides? Hello?

COMMITTEE COUNSEL: Unfortunately, Doctor, I don't think that we have the ability to do that now.

DR. KOMAROFF: I see, well, I will just [INAUDIBLE]...

CHAIRPERSON CABÁN: But, Doctor, you can... You can submit them along with your written testimony.

DR. KOMAROFF: Good, that's what I'll do.

COMMITTEE COUNSEL: We'll send information that will be posted on the website as well, apologies, and thank you.

DR. KOMAROFF: Very good.

My name is Anthony Komaroff, thank you very much for having me testify today.

For about 45 years, I have been studying the problems, the chronic illnesses that follow after many kinds of infelicitous illnesses very much like what happens following COVID.

I wanted to make a few points today. First, these post-COVID illnesses are likely to cause a very large financial burden to society and to governments.

The condition called Long COVID, in particular, which is one of the post-COVID illnesses, has been found to have multiple underlying abnormalities in the body. It is not imaginary. There is now robust scientific research that shows that.

There is a very large research effort underway at both NIH and CBC to understand these abnormalities better, and hopefully to develop effective treatments based on the abnormalities.

After COVID, there are a lot of things that go wrong. For one thing, there are increased rates of several major illnesses. For example, in the year following COVID, the rates of heart attacks, lung failure, diabetes, and early deaths increased by a 150 to 400%. These are new illnesses in people who never had these illnesses before.

Second, there are new kinds of injuries to the heart, lungs, brain, kidneys, that are being caused by COVID.

And, then, last, there is the condition called Long COVID, which also has underlying biological abnormalities -- which several of you have described so clearly that there is no point in my repeating that.

There are major economic implications from this. I am now going to give you the summary of several recent reports, one from the Brookings Institution; one from the Centers for Disease Control; one from the National Borough of Economic Research; and finally an analysis done by two very well-known economists, David Cutler and Larry Summers.

They estimate there are now 16 million adults in the US who have post-COVID illnesses. And then about two to four million of them are out of work because of those illnesses. That is nearly two percent of the total civilian labor force.

The annual cost of forgone wages in this group is $170 to $230 billion per year. The annual cost of medical care and lost quality of life is $544 billion a year. And the aggregate cost to the United States over five years, is estimated to $3.7 trillion.

Who gets Long COVID? It can be more likely to occur in people who were sickest when they first got COVID; however, it can occur even in people with the mildest initial COVID illness.

The risk for Long COVID is greater in women and also in older adults, people with chronic illnesses, and people who are in underserved communities.

What's going in the body in these patients? In the brain, the autonomic nervous system that controls heartbeat, breathing, and lots of essential bodily functions, is malfunctioning.

The small nerves of the body are disordered -- they have a neuropathy.

There is evidence of inflammation in the brain, the death of brain cells, and reduced brain size.

There are autoimmune disease manifestations -- particularly a variety of antibodies against parts of our own biology -- not against foreign invaders.

There is immune cell activation and exhaustion.

In the heart and blood vessels, there are abnormalities that cause the blood vessels to form clots more easily and to go in to spasm more easily -- both of which raise the risk of heart attacks and strokes -- and there is reduced ability to exercise.

Finally, energy metabolism, the ability of the cells of the body to make energy molecules is impaired.

What's being done to reduce the burden of these chronic post-COVID illnesses? As I said, there is a lot research underway, the main purpose of which is to understand the underlying biology to find

biomarkers that can service diagnostic tests for Long COVID, and to find targets for new drugs that may be effective.

There is also research on prevention primarily on vaccines -- trying to find vaccines that produce durable, long term protection... (CROSS-TALK)

CHAIRPERSON MOYA: Excuse me, Doctor?

DR. KOMAROFF: with one shot and a nasal spray.

Yes?

CHAIRPERSON MOYA: If you could just wrap up? We just have some panelists after you that have some time constraints. Thank you

DR. KOMAROFF: Sure.

And, there are trials underway of various drugs.

So, in summary, we have a problem with very large burdens of suffering, and very large economic implications that all governments, unfortunately are going to have to grabble with.

Thanks very much for your time.

CHAIRPERSON CABÁN: And, thank you so much, Doctor. And particularly a gap on an area that we have not heard enough about is certainly the economic impacts. And, so I would encourage you, please do submit, uh, written testimony including those slides

that you were hoping to present. We would really, really love to have them and benefit from learning more from your expertise. So, thank you for being here today.

DR. KOMAROFF: You're welcome, thanks.

COMMITTEE COUNSEL: Apologies, this concludes the second panel.

CHAIRPERSON CABÁN: Oh, I just want to say thank you to the folks who testified, and particularly thank you to -- is it JD?

COMMITTEE COUNSEL: Yes.

CHAIRPERSON CABÁN: JD Davids, Kimberleigh Smith, Juan Pinzon, and Mae Smith, and especially for all of the recommendations that were made particularly by JD Davids and Kimberleigh Smith. We are going to take those in to advisement and ask the administration about those things. So, thank you again.

COMMITTEE COUNSEL: And before I read the names of panelists for panel three, just a reminder that we also have an email that you can also submit written testimony up to 72 hours after the start of the hearing. The email address to submit written testimony is testimony@council.nyc.gov.

And, Doctor, for example, if you have your slides, one of our staff members is reaching out about those slides and submitting, but staff is also available to answer any questions.

So, now I will read public panel three and the panelists' names in order. We will be calling you one by one, but panel three will be Gabriel San Emeterio, and Gabriel is testifying on behalf of themselves, and then two other individuals who are testifying anonymously, and also reading Dr. Levine's testimony into the record in person. And so we will be using separate three minute clocks for that.

Then we will move to Therese Russo, Myra Batchelder, and Rachel Robles on this panel.

CHAIRPERSON CABÁN: Right, and, my apologies, but very, very quickly, I am going to run out for a super quick bio break, and I will be right back, and we can get the next panel set up.

COMMITTEE COUNSEL: So, uh, we will start moving to the table for panel three and take a short recess, thank you so much, just one moment.

CHAIRPERSON CABÁN: Thank you.

COMMITTEE COUNSEL: Alright, we will now move to public panel three.

The first witness on this panel is Gabriel San Emeterio. You may begin testimony when you are ready.

GABRIEL SAN EMETERIO: Hello, my name is Gabriel San Emeterio, and am a New York City resident and a co-founder of Strategies for High Impact and its Network for Long COVID Justice. I am an LGBTQIA+ gender, queer, femme, Latina immigrant, living with myalgic encephalomyelitis or ME/CFS, which was worsened by a recent COVID infection, which became inevitable due to the abandonment of mitigation measures such as masking in indoor spaces and public transportation. And, by the way, I took Paxlovid, and experienced a severe rebound.

Everyone who gets COVID is at risk for developing Long COVID, and more than half of the people with Long COVID meet the diagnostic criteria for ME/CFS. Many of them are homebound and severely disabled. Therefore, it is a privilege to be here as a member of the communities most affected by this crisis. Long COVID affects women and transgender people at higher rates than any other segment of the population. Hispanic adults are also more affected by Long COVID than any other ethnic groups.

I am here in solidarity with all immigrants, particularly those who are undocumented -- many of them women and femmes fleeing gendered violence, and whose Long COVID symptoms are overlooked and trivialized, and whose stories we never get to hear.

I have experienced the dismissal of my disabling symptoms by a multitude of doctors and specialist. ME/CFS took away my ability to work, but I was denied disability benefits many times.

After losing everything, I was eligible to receive public assistance, because I am HIV positive. Three hundred and seventy-six dollars a month in cash assistance, food stamps, Medicaid, and rent assistance, provided by HASA, the HIV/AIDS Services Administration, saved my life.

These resources are not available to people with an ME/CFS or Long COVID diagnosis. Ironically, I recently lost my benefits, because I had the audacity to work 20 hours a week. The income thresholds for public assistance are very low, and they expect people to survive within under $400 a month in New York City.

Let me be clear, I was able to reenter the workforce, because the pandemic made it possible for

me to work from home. Working remotely is not a luxury, it is a necessity that should be protected by law and available to all New Yorkers living with Long COVID and other disabilities.

Despite being in insurance limbo at the moment, I know that I can get culturally appropriate and gender affirming care at one of NYC's H+H Pride Centers, and that I can get my HIV medications through the AIDS Drug Assistance Program ADAP.

Living with HIV has shown me the abysmal difference in care systems and support that exists for people living with HIV, while is nothing for people living with ME/CFS, and little is being done for people with Long COVID.

I call on the New York City Council [TIMER CHIMES], the Department of Health, and other City agencies to use existing programs created to address the HIV crisis as model to provide housing, health insurance, prescription coverage, and other supports and services to people living with Long COVID.

CHAIRPERSON CABÁN: Thank you.

COMMITTEE COUNSEL: Thank you. And, then, uh, can you please begin with the... We have two individuals that are reading anonymous testimony... Or, the

witness is also reading anonymous testimony for those individuals.

GABRIEL SAN EMETERIO: Yes.

COMMITTEE COUNSEL: So, we will now move to Anonymous Individual One with a three-minute clock. So, you may begin testimony when ready, thank you.

GABRIEL SAN EMETERIO: Okay, this is Anonymous Testimony One.

I am reading the following testimony 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. This is her testimony:

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 Long 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 up to 3.5 times. 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 resting.

Fourth, I also pushed through my early Long COVID symptoms due to medical gaslighting. My primary care provider, despite repeatedly hearing my frightening symptoms, only provided a psychiatry referral for anxiety and a basic bloodwork order.

Fifth, I was only recently 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”. If more clinical education was provided regarding these under-diagnosed illnesses, I would have received appropriate 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 no idea if any of my reproductive decisions were correct in relation to Long COVID. No doctor has confidently told me what the 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 Long Haulers 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. [TIMER CHIMES] And all Long Haulers 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.

CHAIRPERSON CABÁN: Thank you.

COMMITTEE COUNSEL: Thank you so much.

We will now move to Anonymous Witness Two.

GABRIEL SAN EMETERIO: Okay, Anonymous Witness Two:

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, the Department of Mental Health, 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, [TIMER CHIMES] 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 cannot 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 lifelong New Yorkers, who need help. Thank you.

CHAIRPERSON CABÁN: Thank you. And, I also want to give you a beat to, like, take a breath, to drink a little bit of water, because I know... (CROSS-TALK)

GABRIEL SAN EMETERIO: Thank you

CHAIRPERSON CABÁN: [INAUDIBLE] several testimonies in a row, and you've got another one to go.

GABRIEL SAN EMETERIO: And, this time limit is kind of ablest, I have to say, and difficult for people who speak English as a second language -- like me. Okay, thank you.

CHAIRPERSON CABÁN: Yeah, thank you, take a beat. Take your time.

GABRIEL SAN EMETERIO: Okay.

CHAIRPERSON CABÁN: Whenever you're ready.

GABRIEL SAN EMETERIO: I have Dr. Susan Levine's... (CROSS-TALK)

CHAIRPERSON CABÁN: Okay.

GABRIEL SAN EMETERIO: testimony here. So, this is from Dr. Susan Levine:

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 the disease, I have evaluating Long Hauler patients.

I completed my fellowships an Infectious Disease and Allergy 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 a Canadian case definition for ME/CFS, which lays out the necessary clinical criteria to make this diagnosis.

Over 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. craniocervical instability, are also being recognized as other diseases 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 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 the disease, but to feel specialist, such as cardiologist, 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 healthcare professionals, family, employers, and disability companies, including the federal government, can recognize the devastating effects of this illness which is so many ways resembles the natural history of ME/CFS.

Not only do we need more healthcare professionals 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 Mailmen School of Public Health, led by doctors Lipkin and Hornig, in addition to other clinical collaborators across the country, that there are a myriad of immune, metabolomics, proteomic, and microbiome abnormalities in me/CFS patients. We can capitalize on those [TIMER CHIMES] 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 medication's, supplements, other treatment modalities, including acupuncture, and some supplements with mitochondrial enhancing effects that would be considered "off label". For instance, several ongoing studies and Long-Haul COVID feature of the use of metformin and atorvastatin, glucose lowering and lipid reducing drugs respectively for their anti-inflammatory benefits.

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

CHAIRPERSON MOYA: Thank you.

CHAIRPERSON CABÁN: Thank you. And, I just want to thank you again for your willingness and the labor of reading multiple testimonies...

GABRIEL SAN EMETERIO: Thank you.

CHAIRPERSON CABÁN: here today. We are deeply, deeply grateful.

GABRIEL SAN EMETERIO: Absolutely, thank you for having this hearing.

CHAIRPERSON CABÁN: Thank you so much.

And as a reminder, uh, we will check for any witnesses that we've missed today online, who are registered, at the end of this hearing. But, you can also submit written testimony to testimony@council.nyc.gov.

We will now move to the next witness on this panel. We have several witnesses left: Therese Russo, Myra Batchelder, and Rachel Robles. Apologies again for any pronunciation issues.

The next witness is Therese Russo, you may begin your testimony when the sergeant calls the clock.

SERGEANT AT ARMS: Time has begun.

THERESE RUSSO: 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) My career background is in and health policy and advocacy.

Every day, I am a community with people whose lives have been deeply impacted, if not devastated by complex chronic diseases like those now developing from Long COVID.

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".

I am here to testify, as others have that there is a second 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 Cabán 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.

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.

As Dr. Levine's testimony just stated, ME/CFS is a disabling, chronic neuroimmune condition that often follows a viral infection. Seventy-five percent of us are not able 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 follows physical or cognitive exertion and leads to a reduction in functional ability. 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.

ME/CFS is often comorbid with autonomic nervous system dysfunction (dysautonomia), another poorly understood set of disorders that can be highly disabling.

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. 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 now also have ME/CFS... (CROSS-TALK)

SERGEANT AT ARMS: Time has expired.

THERESE RUSSO: and/or dysautonomia.

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

Is that time for me?

CHAIRPERSON CABÁN: Yes, if you have a final thought you'd like to wrap up, please do.

THERESE RUSSO: To wrap up, I'd like to say that 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. In this time period, I many new community members who joined us after getting Long COVID. I met 30 year olds who were runners 2 years ago, and who are now in power wheelchairs. I met people whose voices or lungs were too weak to scream chants, who after two hours in the heat had to retire to bed for days, who are still in bed now four days later. This is my community, it's growing exponentially, and it's in crisis.

We need the New York City government to track, educate, and take better care of people with Long COVID and associated conditions like ME/CFS.

My advocacy group would love to discuss in more detail with you, what particularly policy and program changes we'd like to see. Thank you

CHAIRPERSON CABÁN: Thank you, and we'd absolutely would love to have those discussions. So, let's make sure that we stay in touch.

CHAIRPERSON CABÁN: Thank you for your testimony.

The next witness will be Myra... My apologies, the next witness will be Myra Batchelder, thank you.

SERGEANT AT ARMS: Time has begun.

MYRA BATCHELDER: Hi, my name is Myra Batchelder, and I live in New York City and work in health policy and advocacy.

I am here to voice my experience with Long COVID and to call on City Council, The Department of Health, and other city agencies to further meet the needs of the many New Yorkers struggling with Long COVID and associated conditions. Thank you for holding this hearing.

I got COVID in March 2020, likely at a crowded grocery store in Brooklyn. My symptoms started out as mild; I kept working, coughing through Zoom Meetings; however, I proceeded to get worse. I was told by several doctors, virtually, that I likely had COVID, but that I should stay home until my lips turned blue and I couldn't breathe.

I was ultimately hospitalized overnight in April of 2020, where I was finally given a pcr test, and learned that I officially tested positive for COVID.

In the weeks and months that followed, I had a wide range of health issues from COVID and Long

COVID. I was sent to the ER, and also saw a series of doctors and specialists. I faced frustrating gaslighting from some doctors.

Debilitating chest pain was one of my worst symptoms for months along with a very high heartrate. Despite these serious symptoms, a cardiologist I saw told me that my symptoms were likely anxiety, and that I should go for a hike. He told me no one had health issues from COVID weeks after they were infected. It felt like blatant sexism and dismissal.

I ultimately found better doctors, and was treated for pericarditis, POTS, dysautonomia, and other health issues brought on by COVID -- but the process took months.

As time has gone on, I continued to face multiple health issues related to Long COVID and see doctors and specialist. I continue to find some doctors are still not very aware of Long COVID and the research.

There is a need for medical education for providers on Long COVID and associated conditions, as well as the need to address gaslighting and biases amongst providers.

There is also a need for more public education on Long COVID. I regularly hear from people who either

themselves or have loved ones struggling with health issues after COVID and don't know where to turn. A number have had their doctors dismiss their symptoms.

Gaslighting is not acceptable, and it can be dangerous. Some patients may have life threatening health issues after COVID such as myocarditis, blood clots, and pulmonary embolisms.

There is also a for more research, research funding, and treatments for those of us with Long COVID and associated conditions such as POTS, dysautonomia, ME, MCAS, and more.

There is also a need to make sure everyone has access to the medical care and treatment they need. Everyone should be able to access needed specialists and care regardless of their insurance.

There is also a need for additional financial and other supports for those who are struggling. This is just my experience. There are a hundreds of thousands of people in New York City experiencing Long COVID.

There is a need for more community assessment in New York City to better understand what's happening with the Long COVID community -- and what additional policies and programs can be put in place to help.

We need The City Council, The Department of Health, and H+H to take action to put in place addition policies and programs, and to provide more support to those struggling with Long COVID and associated conditions. [TIMER CHIMES]

SERGEANT AT ARMS: Time has expired... (CROSS-TALK)

MYRA BATCHELDER: We also need the City... Yep, just... We also need the City to take additional actions to prevent more people from getting COVID and Long COVID, as well as from getting re-infected and potentially getting worse.

Vaccines are essential, but not enough on their own. We need a need a multi-pronged approach including reinstating masks mandates, free N95 masks, improved ventilation infiltration, and more. Thank you.

CHAIRPERSON CABÁN: Thank you.

COMMITTEE COUNSEL: Thank you for your testimony.

We will now move to the final witness on this panel; this will be the final public witness; although, we will check for anybody that we have inadvertently missed before concluding the hearing.

The final witness is Rachel Robles. You may be... Rachel Robles, you may begin your testimony when ready... when the sergeant begins the clock.

SERGEANT AT ARMS: Time has begun.

RACHEL ROBLES: 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 New York City. 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, and your congressional actions.

In a world that tries to ignore disability...

(CROSS-TALK)

SERGEANT AT ARMS: Time as expired.

RACHEL ROBLES: we refuse to be ignored.

CHAIRPERSON CABÁN: You can finish your statement.

COMMITTEE COUNSEL: Go ahead and finish.

RACHEL ROBLES: In a world that tries to ignore our disability, we refuse to be ignored.

CHAIRPERSON CABÁN: Thank you.

CHAIRPERSON CABÁN: Thank you for your testimony.

This concludes our fourth and final panel. We will now check to see if there is anyone that we inadvertently missed. If there is anyone logged in to Zoom that we did not call, and who registered, if you can please use the Zoom Raise Hand Function? We will wait just one moment.

Okay, we have no hands, we're not seeing any hands, and we have heard testimony, we believe, from everyone who has registered. If, again, there are any questions, or if you have written testimony, please feel free to reach out to staff. And written testimony can be submitted to testimony@council.nyc.gov .

We will now move back to the chairs to close the hearing, thank you.

CHAIRPERSON CABÁN: I just want to thank everybody again for their testimony on this really, really critical issue.

It is just so abundantly clear that we are facing an enormous crisis and do not have the infrastructure and resources in place to support folks.

So, we have a lot of work to do, and, again, we are just deeply grateful for the folks who came here brining their expertise, their knowledge, their personal experiences, to help us, certainly in The City Council, try to devise and implement some plans to address and start to alleviate some of the things that folks are experiencing -- and acknowledge the fact that it is women, BiPOC folks, queer, trans, and gender non-conforming people who are bearing the brunt of this.

So, thank you again, and thank you to all the staff for all your work in helping to make this possible.

[GAVELING OUT] [GAVEL SOUND]

This hearing is now adjourned and concluded.

C E R T I F I C A T E

World Wide Dictation certifies that the foregoing transcript is a true and accurate record of the proceedings. We further certify that there is no relation to any of the parties to this action by blood or marriage, and that there is interest in the outcome of this matter.

Date September 15, 2022