On the eve of Long COVID protest: An interview with Julie Lam, photographer and founder of MaskTogetherAmerica

Benjamin Mateus
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On March 15, 2024, grassroots organizations of Long COVID patients, allies, and other "COVID cautious members" are planning a Long COVID awareness day in Washington DC at the Lincoln Memorial. Their stated purpose is to raise awareness of the crisis caused by the COVID pandemic. Specifically, they are calling for "change, action, and transparency from our government and healthcare officials."

The World Socialist Web Site *was contacted by Paul Hennessy, one of the organizers of the event, because of our principled stand on the pandemic and the need for an international elimination strategy and call for deployment of massive resources for public health to address the crisis caused by COVID and Long COVID.*

In the process we were introduced to Julie Lam, a photographer and founder of the non-profit organization, MaskTogetherAmerica. She has used her experience as a professional photographer and her work in advertising to promote mask wearing at the start of the pandemic.

In 2021 she contracted COVID and developed Long COVID, which has caused continued and significant debilitation. She gave this interview to discuss her work, her own experiences with Long COVID, and the political failings of the Biden administration.

Benjamin Mateus (BM): Despite what President Biden said at the State of the Union Address, "the pandemic is behind us," COVID and Long COVID continue to plague the US and the rest of the world.

The *World Socialist Web Site* has been covering and documenting the pandemic from the beginning. We have raised the issue of the need to eliminate the virus and fund public health. But these require international cooperation, meaning that the reason the pandemic still remains with us has more to do with political brinksmanship and prioritizing profits over lives than the challenges posed by the biological and epidemiological characteristics of the global outbreak.

Certainly, the issue of Long COVID has emerged as a great detriment to the population. On March 15, various grass roots organizations, led by an "ally" of Long Haulers, Paul Hennessy, are planning a Long COVID demonstration in DC at the Lincoln Memorial.

You are a founder of the all-volunteer organization, MaskTogetherAmerica, and will be speaking in DC. Maybe with that introduction, can you discuss the aims of the demonstration, and tell us who you are and how the pandemic has impacted you?

Julie Lam (JL): We were very honored to be approached by Paul asking us to be speakers at the LCDC demonstration. I have been working with a list of advisors.

I am certainly not a scientist. I'm not in public health either. My background is in the arts. I used to work in advertising. I jumped into this at the start of the pandemic like so many other people. I wanted to use my skill sets to convey how the pandemic was impacting regular people. I interviewed and photographed them everywhere I went.

My background was in television. I'm not as used to the different social media formats. I have won numerous awards creating campaigns for corporate America, big companies like TD Ameritrade, American Express and Motorola. I used to work at Ogilvy and Mather [*the New York City-based British-owned advertising and public relations agency*].

But I retired some time ago because my son was dealing with school, and it was very challenging to find help. As a mom, I gave up everything to take care of him. He's now in college.

When the pandemic finally reached the US in early 2020, New York became the epicenter, I just threw myself into all of this. I had recently completed my master's in writing, and thought I could help give voice to what was taking place. Fast forward, it has been four years we've been working on this project. It is all volunteer work. Everyone who has been helping MaskTogetherAmerica are volunteers.

I do the bulk of the work, like the interviews and writing and posting on Instagram or Facebook. We have people volunteer to be administrators and editors to expand our reach. We also create these educational forums featuring experts and scientists so they can share the real science, provide accurate guidelines and answer people's questions, information that people aren't getting from our government. To prepare myself, I have even taken a crash course in public health through free classes that were being offered by Cornell.

Much of this drive in the beginning stemmed from a friend of mine who died early on from COVID. He was a Mount Sinai surgeon and served on the front line of the pandemic. And it was such a shock to me. I just said, "I can't just sit on the couch and do nothing." So, I just went into the streets.

BM: He was one of the first health care workers who became infected.

JL: Yes, Barry Webber is one of the first. [*Died on April 18, 2020, at the age of 67*] He died at home. He had sent his wife and children away so they wouldn't get infected. At the time there were no mask requirements in the emergency room where he was working. Tragically he died alone, like many others.

In the apartment building where I live, so many people got sick. A lot of the people who worked in the building also contracted severe COVID. I even brought them masks to wear. Initially, I didn't really believe in masking. And now you can see all these portraits of people in masks that I took in 2020. I went everywhere to interview people on the street and through these discussions I hoped to empower them to share the message and possibly influence their own circle of friends and colleagues. I didn't have the capital to invest in a massive campaign.

As I said, I initially didn't believe in masking. But my friends in Hong Kong sent me boxes of masks and told me to wear them. They had gone through SARS1 in early 2000 and they said that this is SARS2 basically.

BM: They knew then that SARS1 was airborne.

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JL: They knew. And many of their medical personnel died. They were trying to warn everyone across the world, but we didn't listen.

My friend had sent me a box of masks, and I thought I better start masking. I even gave masks to the workers in my building. Some refused to take them. They said they didn't believe in masking and wouldn't wear them. And I remember talking to this young man who was only 39 years old. He politely refused the mask I offered him. He contracted COVID and fell so ill that he was out for a month. A few months after he supposedly recovered from COVID and came back to work, he suddenly died in his sleep. He never woke up. And he doesn't even get counted as a victim of COVID. I really don't believe in the numbers that the CDC puts out, like how many people died from the disease.

I used to be so trusting of them. We trusted the vaccines, the guidelines, and we promoted them. We did a huge production where people submitted their videos and I put them together to encourage people to get vaccinated. And then I saw Biden say that after we have the vaccine, we didn't have to wear masks anymore. And during the first Omicron wave, Fauci went on television and told everyone that during the holidays, if you're vaccinated and your families are vaccinated, you shouldn't worry about gathering. [*Between Biden's address in mid-May 2021 and Fauci's comments in mid-December 2021, approximately 210,000 Americans died of COVID. Another 190,000 died by mid-March 2022, in the first Omicron wave. In total, 400,000 Americans succumbed in less than one year after the great unmasking promoted by the White House and CDC.*]

I took the vaccines. However, I had a severe reaction to the second dose of Pfizer's COVID vaccine. I have an auto-immune disorder and it worsened my IgA nephropathy [*an immune-related kidney injury*]. I developed severe hematuria [*blood in the urine*] and went from stage 1 to stage 2 chronic kidney disease. My nephrologist prescribed Tarpayo, the only steroid made for IgA patients, but it costs about $16,000 per month. My insurance denied the coverage. I was able to apply for patient assistance and was approved a free supply.

I had gone to see my family on Christmas 2021 and became infected by a family member and afterwards developed Long COVID. I became another Long Hauler. My symptoms are sleep-apnea and Sjogren's, which is an immune syndrome that gives me very dry eyes and mouth.

I still believe in raising awareness about vaccination even though some people can't take them. I was able to convince my doctor to give me the booster but that was the last time because they had damaged my kidneys. And they didn't prevent me from developing Long COVID.

BM: Right. The vaccines, overall, are very safe. But they don't prevent infections. They reduce severity of disease and death from an infection. That's why a vaccine-only strategy is so flawed, especially when immunity is short-lasting. That's why the continued masking, cleaning indoor air, and aggressive public health initiatives are so important.

But this initiative needs to be a global initiative. You can't stop the pandemic in just one country. We all want to resume life without masks and worries, but there is a pandemic that continues to rage. However, the policy in play, which is being promoted by Biden and company, is get back to work, regardless of the dangers or consequences. "Bury the pandemic!"

Did you watch the State of the Union Address? Long COVID was never mentioned.

JL: The pandemic is not under control. It is the abandonment of prevention. It is the abandonment of people. That's what I took from his speech. He completely ignored the millions of people who are suffering from Long COVID. We're expendable to him.

"Vax-and-relax" is the strategy the government has taken on. The CDC just dropped isolation because they wanted people to go back to work. And they wanted to have life back as usual again. But that's not the case for people who are suffering from chronic illness triggered by COVID infection. Those people are not okay.

There is a huge problem with health care in this country. We have uncontrolled drug prices. The insurance costs are insane. The cost of my medications is astronomical. I would have to sell my house to get them if I wasn't able to get them on an assistance program, and that was no easy task. The process took some time. There was so much paperwork I had to deal with and a long wait time before they approved it. I am fortunate that my husband has a good job, and he has good insurance. But even then, they wouldn't cover it.

The Long COVID crisis means a lot of people need comprehensive long-term care. They need to see a lot of specialists. It took me two years to get a diagnosis of my Long COVID eyes that developed after I had COVID. Two years and so many doctors later before I was finally told I had Sjogren's triggered by COVID.

So, I have this diagnosis but then what? There's no treatment for Sjogren's. There's nothing that can make me feel better. And having an eye issue as a photographer and writer means the end of my career, right?

Biden really doesn't get it. You can't say that the pandemic's under control.

You have to talk about Long COVID and the mass disabling event that is a world crisis. You have to acknowledge how many people are getting affected by this, how many young people are getting affected. This means organ damage for these young people. If children die from COVID, that also means they will develop chronic health issues too.

People will listen to the president. If Biden is saying that the pandemic is over, people's attitude will adapt to this. He is sending a horrible message to the world. It's not just to Americans. The rest of the world also look up to America for guidance. This is a wrong message for this whole crisis. He is being very irresponsible. Very shortsighted.

BM: It is important to note that this isn't ignorance on his part. It's purposeful. He is catering to the financial markets. He called himself a capitalist. He owes his career to supporting corporations. He wants to sell a fantasy spewing banality that things are getting better in the US.

JL: One of the things that should happen is a fight for paid sick leave for workers. Instead of dropping isolation, people who are ill should be allowed to stay home and receive pay. I really believe that isolation is an important mitigation tool to stop the spread of the virus. I think the CDC dropping isolation right before the State of Union was done to support Biden's lies that the pandemic is under control even though we just had the second largest wave in January.

It was just a massive public relations effort to make Biden look good in front of the cameras and make the claim that businesses can get their workers back to work. COVID is still a threat. But then he can't raise the issue of Long COVID if he wants to put a check mark next to his list of "Missions Accomplished."

But it's easy to silence people who are sick and dealing with chronic illnesses. Just for my team that is going down to DC to speak at the demonstration, I must worry about Dr. Robi Tamargo coming from Florida, who is so sick from repeat bouts of infections and multiple hospitalizations from COVID. I'm worried she will get another infection on the plane ride. It is very difficult for us—the chronically disabled from Long COVID—to go to DC to protest because it takes every ounce of effort to just get through our days. I'm already having tremendous anxiety just thinking about wearing my mask on this long train ride and staying in a hotel over the weekend. It isn't easy for us to travel alone. It is a huge effort for all of us.

I don't know how many people will show up for the Long COVID demonstration, but I have all these people that have stepped up with me for MaskTogetherAmerica. I am going to do my best to be there for all the people that can't make it.

BM: Four years in, where are we with Long COVID with regards to getting a valid diagnosis and approved disability ratings, treatments,

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ongoing studies, and, generally, acceptance by the health care systems?

JL: We are still dealing with gaslighting. Many people without good health insurance aren't going to be able to get a diagnosis. They're not going to get through the process. It took me two years. Initially I had shooting pain in my eyes. My doctor kept sending me to different specialists, but nothing materialized. I added 10 more doctors to my list and the costs of all these visits and evaluations were exorbitant.

BM: From what I have heard, most are told there is nothing wrong with them. They can't help them. Go see someone else.

JL: Maybe. I can't speak for everyone, but I know that people are not getting paid for the care they need. They're being bounced around. And from my own personal experience, I told my primary care provider to stop sending me to another specialist.

Though I qualified for the assistance program for Tarpayo, I didn't take advantage of it because by the time the approval came, I had joined a medical trial for a drug called Vera. It is an immune modulator. But because it is a randomized controlled trial, I could be receiving a placebo.

For my Sjogren's, my rheumatologist started me on a nasal spray called Tyrvaya (varenicline) to treat dry eyes. But it caused such severe insomnia I had to stop the treatment. I couldn't sleep for a few days. But that's just more proof that there's no treatment for my condition. My rheumatologist said that I'm not alone either. She has a lot of other patients who also come to her after having COVID.

BM: Long COVID is complex disease process and we've never seen it on this scale. But we have to figure it out. It requires research. It requires investment. But they say there is no money for these trials and experiments. Together with this, we must prevent Long COVID through preventing COVID.

JL: I wanted to add that what upset me about the CDC's COVID guidance is they have lumped COVID together with flu and RSV, which is so wrong. When you say that the symptoms are mild, like cold symptoms, you're basically minimizing the severity of the impact on the organ system.

It sends a message that it's not really that serious, which will discourage people from taking the vaccines and treatments. If I want to increase vaccination uptake and masking, I'd be showcasing long haulers. Just like the anti-smoking campaign showcased people with incurable cancers caused by smoking. Interview the families of people who died of COVID. Speak to people struggling with Long COVID. Let them tell their stories. It would be very sincere and authentic. I really believe that public health needs to be grounded in authenticity. You need to be truthful.

BM: I think your comments are very powerful and will resonate with readers of the interview.

Dr. David Putrino from Mount Sinai, who had conducted extensive work with Long COVID patients, recently mentioned in a webinar held by the New York State Insurance Fund on Long COVID, that the prevalence of Long COVID seems to be higher among more affluent layers. But he did state that this was a reporting bias, meaning the working class and low wage earners don't have access to health care nor understand why they feel poorly. The issues we are raising today must be taken deeper into the working class, where the impact of the pandemic has been made more invisible than among those who can afford to traverse the health care landscape.

JL: I can tell you that I have been the reporter for COVID. Look behind me at the faces of masked individuals and multiply that by four years. I have talked to thousands of people. I met people in the subway. I talked to them on their way to work.

They have lost their memories. They lost their taste and smell. They are terrified. They don't want to get COVID again. That's why they were wearing masks.

But they keep on getting the message from the government that it is milder now. All these strains are milder. All these lies that they got from the government are confusing the world. Instead of putting out posters in subways to tell people you should protect your health by wearing a mask, they did nothing for these people who are just getting sicker and sicker.

Over the four years I've seen so many people getting multiple infections. Dr. Tamargo, a clinical psychologist in Jacksonville, Florida, who will be speaking at the demonstration, has been infected seven times. Their immune system has been so damaged. It's a horrible thing that our government has done to people, and they really don't care.

BM: And as you noted, what happens in the US is copied and duplicated in other countries. This is not an American issue. It's an international issue.

JL: Yes, international. I've traveled to UK and Berlin recently. Nobody is wearing masks. But I talked to an Uber driver. He said their situation is better than in the US because they have a social network. If they get sick and disabled, they can get housing, food and paid leave while they recover. But if you talk to a restaurant worker or Uber driver here in the US, these people can't afford to be sick.

BM: Any final comments you'd like to make?

JL: I think there are two things we really need urgently. We need to have a proactive prevention strategy. Our government needs to endorse a proactive prevention strategy which means we also need them to provide the mitigation tools for people.

Lastly, they can't say they are serious about Long COVID unless they embrace a serious mitigation strategy.

I listened to the entire subcommittee hearing on Long COVID and all these politicians agreeing that Long COVID is a health crisis. This is serious. Bernie Sanders said that this is the biggest thing in our country right now. But on the other hand, you see them all without masks and not taking COVID seriously.

BM: It's political theater.

JL: That's a perfect way to put it. I always said that whatever these people are doing is all for show. I don't buy it, what they are trying to sell.

BM: Thank you, Julie for your time. I look forward to hearing you speak at the demonstration.

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