

Lisa McCorkell

Behind the Mask

April 27, 2023

**Barr**

Good afternoon. Today is April 27, 2023. My name is Gabrielle Barr, and I'm the archivist with the Office of NIH History and Museum. Today, I have the pleasure of speaking with Miss Lisa McCorkell. Ms. McCorkell is a long COVID patient, as well as a long COVID advocate. Thank you very much for being with me.

**McCorkell**

Thank you for having me.

**Barr**

Definitely. Will you relay what was your experience in the acute stages of COVID-19 in 2020, and what the symptoms were that made you consider that you may be experiencing long COVID, and have the symptoms remained the same?

**McCorkell**

Sure. I got COVID in March of 2020, very early on. March 14<sup>th</sup> was my first day of symptoms. It was just a few days, even before lockdowns really started. My initial symptoms were fatigue, cough, shortness of breath and some brain fog. But because I had fairly mild symptoms and didn't need to be hospitalized, and also didn't have a fever, I wasn't able to get a COVID test. My health care provider just told me to isolate from my roommates and within a couple of weeks, I should be better. That wasn't the case, though. I kept staying sick, and actually got quite a bit worse in the weeks after. I continued to have fatigue, brain fog. The biggest change in those first initial weeks after the acute COVID infection, was that after even for a five-minute walk, I would have an exacerbation of a lot of my symptoms, so I'd have shortness of breath, my heart would race, I would be so fatigued I'd have to be in bed the rest of the day and the next day. This was very different than what I was before getting COVID, I was a big runner. I'm not used to feeling that way after any type of exertion. So, it was around that time, maybe a month when it really felt like I'm not really getting over this, it seemed to be continuing. I didn't know at that time, we didn't have a name for long COVID. But I read an article in The New York Times from Fiona Lowenstein, who documented their own experience with these prolonged symptoms and started a support group. I joined the group and was very validated by seeing how many other people were experiencing this. But it's been three years, over three years since I first got COVID. My symptoms, they've kind of changed a little bit, but largely what I'm left with [is] I have a diagnosis of Postural Orthostatic Tachycardia Syndrome or POTS. It's a form of dysautonomia. I have premenstrual dysphoric disorder, where for the week before my period, I have extreme depression and anxiety and suicidality, and then I have post exertional malaise. So that's kind of what has been remaining.

**Barr**

Do you have any underlying conditions? Because you said you're young and a runner, so it's surprising it hit you so hard?

**McCorkell**

The only thing I had known about was celiac disease. That's the only condition I had diagnosed prior to COVID.

**Barr**

What has it been like for you to get care for COVID given that you didn't have the opportunity to have a positive test? I know that some people really struggled to get care, I believe because they don't have that in hand, which is a tragedy.

**McCorkell**

Absolutely. That has been my experience as well. I had some good care for first few months; my health care provider at least believed in me and believed what I was going through but didn't have many solutions to offer me, not really know what was going on. Then I had to change insurance, and my new health care providers after that were very skeptical that I even had COVID in the first place and said that my symptoms were, you know, just like, basically made up. They dismissed what I was going through, and that really led me to not seek health care for a long time because it felt like kind of a waste of time; it was a waste of money. You know, no one wants to go to the doctor and just be completely dismissed for the concerns they are going for. Since then, I've sought additional health care, and I've had mixed reactions. I think in the last year it's gotten a lot better since more providers know about long COVID, and I'm able to educate them on it, but I'm still unable to access a lot of long COVID clinics. I haven't been able to access the one that's closest to me in my health care system because of that lack of a positive test. That has really been a big barrier to care.

**Barr**

Definitely. How has long COVID impacted your daily life, and what have been some mechanisms that you have found that have allowed you to cope these past three years?

**McCorkell**

Yeah, so it really has. I'm a mild case of long COVID, and it still impacts my day-to-day life. I can't stand as long. If I'm cooking, for example, I sit down; I need a lot of rest. I try to pace myself. That's one of the things that has been most helpful is that before and after exertion, I rest a lot. But that also has a big impact on your day-to-day life and is a big change from what I was doing before; I didn't necessarily need that. I used to be, like I said, a runner, and I can't do what I used to do for exercise anymore, I can't work as much. The premenstrual dysphoric disorder has really been the most severe part of my long COVID. Having those mood symptoms has been pretty impactful for that week when I have it every month. In terms of mechanisms that have that allowed me to cope, it's that pacing, working remotely has been huge and enabled me to continue working, having a flexible schedule. Having a support system of friends and family and then people with long COVID who understand what I'm going through has been hugely helpful.

**Barr**

Would you discuss the value of patient-led research as well as its challenges, and the impetus for you and joining others in your situation and launching the Patient-led Research Collaborative (PLRC).

**McCorkell**

Yeah, so from our perspective, and our experience, patients know their body best and are the most motivated to find answers. Patients have hypotheses for research based off their own experience and doing research themselves. Also, patients understand really the best way to ask questions and design a study so that it reflects the patient experience. I think having patient-led research and research that really meaningfully engages patients is what's going to get us to answers faster and get answers that are more accurate and reflective of what patients actually go through, but it often isn't valued among traditional researchers and medical professionals; we often run into skepticism. A big challenge is getting people to understand our value. And yes, that was part of the impetus for starting Patient-led Research Collaborative. At the time and early on, like mid-2020, no one was talking about long COVID or studying long COVID. It was really patients that were the only ones talking about it and people who were experiencing related post-viral illnesses. We realized that we needed to figure out solutions for ourselves. That was really the impetus for starting PLRC.

**Barr**

Will you discuss the initial surveys that PLRC disseminated including how you all recruited responses and criteria for taking part and what you all learned from the results?

**McCorkell**

Our first survey was done in April 2020. And that one, we largely just promoted it to the Body Politic COVID-19 support group. That was the group that we had stemmed out of who we knew was experiencing symptoms like we were. The criteria for taking part were a suspected or confirmed COVID infection, either one. In that survey, we identified 62 symptoms of long COVID. It was the first survey to really identify neurological symptoms after COVID. At the time, COVID was largely considered a respiratory-only infection. But that was only just like, you know, people had max three months of symptoms at that point. Then we did a second survey in the fall of 2020 to document the longer-term symptoms. That one was more expansive as we had both experienced more symptoms ourselves, and we were hearing things from the patient community. When we identified 200 symptoms of long COVID, we looked at the impact on work, and found that two-thirds of people had some type of impact, where either they could no longer work or had to reduce their hours. It documented the multi-systemic nature and some of the triggers of exacerbation of symptoms. For that one, we were able to recruit, and we still do, through social media. We expanded beyond the Body Politic COVID-19 support group, and we're able to promote it to other support groups that had popped up, long COVID support groups, and really tried to get an international view. It covered many countries; we translated the survey into nine different languages and tried to get a more representative view of long COVID.

**Barr**

Are there plans to create another survey given that it's been a couple of years since even the second survey, to see how people are doing now?

**McCorkell**

Right now, we have a survey out about reinfections. It's looking at the impact of getting reinfected on people who have long COVID, as well as looking at if people didn't develop long COVID after their first infection, did they develop it after a subsequent infection? That's what we have right now.

**Barr**

I thought one thing that was very interesting was the importance, especially in the early, early survey, of using Slack and communicating with others. Then some people used some of these Slack conversations to go to their physicians and healthcare providers to prove that others had the same symptoms. Can you comment a little bit about that?

**McCorkell**

The Slack group is the Body Politic COVID-19 support group; it's unfortunately shutting down now but for the last three years has really been a huge lifeline for information sharing and support. And that was where we stemmed out of, that was, you know, many thousands at this point, people with long COVID have shared their experiences and have been validated by other people sharing their experiences. And that has been a huge source of information sharing that people with long COVID can take to their doctor [and say], "This is being experienced by other people. Here's a treatment this person tried; I would like to try it." Just getting more information and really bringing the community together and helping many of us to come up with hypotheses for what could be going on.

**Barr**

What has the reception been to your efforts, as well as the efforts of others, in terms of presenting in front of the World Health Organization, CDC, NIH, and the United States Congress that has been mentioned in countless articles, in terms of all your work on long COVID?

**McCorkell**

Reception has been mixed. It's been largely a good reception. I think the organization PLRC has been taken seriously, I think, because we have a lot of the skills and backgrounds that are considered valued by the field, though we would like to change that dynamic and just have the patient experience be enough to be valued. I think that we're invited to a lot of these big organizations to give input and to describe the experience of long COVID, but we're still not seeing a lot of action. I think that's why I say the reception has been mixed is because not all of our recommendations are taken; a lot has been moving fairly slowly. Some don't consider long COVID to be a big issue. Then there's also the minority of people who are minimizers of long COVID or more focused on traditional research. I think we've been very lucky to be in a lot of these rooms and get invited, but I would have liked to see more action and more sense of urgency from these organizations.

**Barr**

Can you speak a little about how the Patient-led Research Collaborative contributed to the NICE, the National Institute for Health and Care Excellence guidelines on long COVID?

**McCorkell**

We were reached out to the National Institute for Health and Care Excellence, to provide feedback on the guidelines. We gave our comments; some of those were incorporated and some were not, but we helped to shape it as best we could.

**Barr**

Definitely, can you discuss your role in a Community Engage Qualitative Descriptive Study involving online semi-structured interviews and participant voter illustration of adults from the United Kingdom, Canada, Ireland, and the United States from the December of 2021 to May of 2022, and what you hope this study accomplished for a long COVID research and patients?

**McCorkell**

This is a really awesome study. So, Patient-led Research Collaborative, we're one of a few community groups that are involved in this. We serve on an advisory board of sorts, where we help guide the protocol development of the study, we oversee the analysis and the writing, based off on our lived experience, and what we hear from the patient community. The study aims to capture the episodic disability nature of long COVID. Most of us have a baseline of symptoms that we are always experiencing, but then we have periods of crashes. There are other aspects of the disease that can wax and wane. This study really is a great qualitative look into what that experience is like, and how we can better capture that experience of episodic disability and future research in diagnosing and treating the disease. I think it will be really helpful in order to inform future research.

**Barr**

Are you involved in any other studies or hope to be involved in any other studies like this?

**McCorkell**

Yes, we're involved in a few other studies. Honestly, I can't think of them right now, having some brain fog.

**Barr**

That's okay. What was it like for you to be a part of medical and scientific research because that was not your background before you became ill? Can you speak about what it's been like for you to enter this realm?

**McCorkell**

It's been interesting and a big learning curve, but I think, what I've seen, what I've been able to take from my background, which is in policy, and informing public policy, one of the best ways to do public policy is to have a community-based participatory research approach. If you're developing policies, really asking the communities what that policy is going to impact what their issues are, what the problem is that you're trying to solve, and what their suggested solutions are. That's the world that I came from. It felt very natural going into medical and scientific field to have this background, you know, the community that's impacted be right at the forefront, and in partnership with the decisions and research being done. I think it's always a learning curve for the medical background, scientific terms, and trying to be on the same page as researchers who have MDs and PhDs, but, because I've experienced this, there's so much value in that piece. I've just kind of thrown myself into learning about the disease. I've tried to learn as much as I can, so I can consult with experts that I trust, and have them educate me on the different medical and scientific aspects.

**Barr**

What have you found most interesting about it since you began to be part of these discussions?

**McCorkell**

I think what's most interesting is just how much overlap there is of long COVID and conditions that we've known about for a long time. These include myalgic encephalomyelitis/chronic fatigue syndrome, POTS, which I have a diagnosis of, fibromyalgia and more. There are other aspects of long COVID. There's organ damage; there's other things. I think seeing the overlap and how much research there exists in these fields, a lot of those have been very underfunded but we still know quite a bit, I think that's been both interesting and also sad. I think if we had really focused on those conditions prior to COVID, we would be in a much better place in terms of long COVID research.

**Barr**

Definitely. When did you become involved with the adjudication committee of NIH Health RECOVER Initiative, and what are your responsibilities as part of this group?

**McCorkell**

So, RECOVER invited me to be a patient representative, starting back in summer of 2021, when they first launched the RECOVER Initiative. Then they had the opportunity to join different committees, I think it was in late 2021. Then I joined the adjudication committee in February of 2022. As part of that group, I'm one of two patient representatives of the group. We have looked at the kind of changes to symptom surveys, to make the surveys more representative of—sorry, not the symptom survey, the comorbidities survey—to make it more representative of the patient experience. Although we haven't actually met that many times, we haven't had that many tasks as a committee, but the responsibilities are to attend meetings and give feedback and really provide that patient perspective, that patient voice. I've also been involved with some of the manuscripts, including the first look at the symptom analysis that will be published pretty soon.

**Barr**

That's exciting. They're going forward. Do you hope to be involved in more ways?

**McCorkell**

Yeah, I think that it's been it's been a tough experience being part of the RECOVER [ Researching COVID to Enhance Recovery] Initiative in some ways because there are some people involved who don't necessarily value the patient experience, or we don't have as much input as I think is really needed. But I'm hopeful that is getting better, and I think if we continue to see improvements in that area, and we're able to get seats at the table on the steering committee and some of the higher-level committees, I think it's worth it to be more involved.

**Barr**

Definitely. You speak about all the different ways that you've championed for a long COVID issues from interviews to social media. How do you hope to reach a more underserved populations in the future?

**McCorkell**

We've had so many opportunities, and I do what I can with my energy in the day, but I think it's really a testament to the patient community together that has successfully brought the issue of long COVID to the attention of the government and the press. We together initially got the funding for RECOVER; we have really brought attention to [the Department of] Health and Human Services and have partnered with them on having an office for long COVID. I think there are limitations to what we can do as a patient community that is sick and has limited energy, but for what we have been able to accomplish in the last three years, I think we've done what we can, and I hope that we can continue to partner with government to do even more and address the urgent issue. In terms of the most impacted populations of COVID, generally, are communities of color and low-income populations. That is reflected in who has long COVID; we see in the Household Pulse Survey that Latinos have the highest rates of long COVID. We really need better ways of reaching these populations. I think that would include having more partnerships with community organizations and getting community health workers into communities to talk about long COVID and provide information and treatment options to folks who are experiencing this but may not have regular access to health care and who may not even know that they are experiencing long COVID.

**Barr**

Can you speak a little about the long COVID protests that you took part in?

**McCorkell**

Sure, this was in September, October of last year. It was hosted by ME Action, which is an advocacy group of people with myalgic encephalomyelitis/chronic fatigue syndrome [ME/CFS], they have this event every year. It's called "Millions missing," and it's really to draw attention to the lack of action that the federal government has taken in addressing ME/CFS, and we see that now with long COVID, where about half of people with long COVID have ME/CFS. The protest was also in direct response to President Biden saying that the pandemic was, quote, unquote, over. For millions of us, it's not over; we have long COVID. We are still experiencing the effects of our COVID infection. We're at high risk if we get reinfected. We know that as COVID cases continue, more people are going to develop long COVID. The pandemic is not over by any means. COVID continues to spread; we're still going to be in the midst of this mass disabling event. The protesters really [brought] attention to that and to the needs of people with long COVID

**Barr**

Three years into the pandemic, what in your mind have been the positive steps taken to understand long COVID and alleviate it and what do you think still needs to be addressed from many different standpoints including from NIH and RECOVER?

**McCorkell**

While we still need to better understand underlying mechanisms of long COVID, we have learned so much over the last three years; there's been a lot of research done on long COVID. It's been remarkable to see how many researchers have turned their attention to this. At the same time, we have very few clinical trials happening, there hasn't been a huge focus on therapeutics, which is what improves quality of life for people with long COVID. We have no financial support, disability benefits are extremely difficult to get on. People are denied

work accommodations, and then even just provider and public awareness have been lacking. I think that more providers are aware of long COVID but often give harmful advice to people who are experiencing this. We really need increased awareness of that. Even the public is not fully aware of what long COVID is, which prevents them from making informed decisions about their own actions around, risk of getting COVID. If they're experiencing symptoms after COVID infection, they may not know that it's long COVID. Especially with NIH, I think it's really important to have an office that is dedicated to long COVID research and research of associated conditions that can oversee all of the research being done, that overlaps on these conditions, that helps create a research plan so that researchers can communicate, to have really dedicated funding towards this. This is an issue that is not going away, but it's only going to increase and to focus on clinical trials and funded clinical trials that are testing therapeutics. These are issues that are of real importance to the patient community and have basic and existing evidence.

**Barr**

Is there anything else that you would like to share either about your experience or long COVID in general?

**McCorkell**

I don't think so.

**Barr**

Well, thank you very much for all the work that you have done on behalf of long COVID patients with NIH and as well as with other groups and I wish you only the best, and hope your symptoms subside.

**McCorkell**

Thank you so much.

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