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0:00:00.1 Abby Dumes: Hello all. Welcome to today's webinar, "Stories of Long COVID advocacy in the United States." We are so, so glad to have all of you here. My name is Abby Dumes, and I will be today's moderator. My pronouns are she/her, and I am a white person with brown hair, and I am wearing a red and blue patterned shirt. I'm also an assistant professor in the Department of Women's and Gender Studies at the University of Michigan, and a core faculty member of the Global Feminisms Project. We have a few important items of note before we begin: captions are available by clicking on the "show captions" at the bottom of your Zoom screen. This webinar is also being recorded. The video recording will be posted on the Global Feminisms website after this event and emailed as a link to all registered attendees as well. There will be time for questions at the end of the webinar, so please post your questions for the panelists in the Q and A box as you think of them, and please also review the Institute for Research on Women and Gender or IRWG's free speech guidelines for virtual events, which our wonderful event coordinator, Heidi Bennet, is pasting into the chat right now.

0:01:24.2 AD: And then finally, a million zillion thanks to the staff at the Global Feminisms Project and IRWG for all the amazing work that they've done in preparation for this event, and of course, the panelists here today who have generously offered their time and expertise, and whom it's my honor to now introduce. So, in alphabetical order. We first have JD Davids.

0:01:50.7 JD Davids: Hi, I'm JD Davids. My pronouns are he/him, and I'm a white person with medium brown hair, wearing wired headset and a red hoodie, and I'm here today in solidarity with the University of Michigan grad students who are in open bargaining right now for labor rights, including COVID safety protections they're denied in the classroom.

0:02:12.5 AD: Thank you, JD. JD Davids is a US-based health justice and communication strategist, working with national networks of disabled and chronically ill people. He co-founded strategies for high impact and its Network for Long COVID Justice in 2021. Davids has been an external expert advisor to the NIH, CDC and local health departments, and has served as a strategist and organizer with many pivotal groups, including ACT UP Philadelphia, AVAC, the Coalition for a National HIV/AIDS Strategy, Health Gap, The Health Not Prisons Collective, The HIV Prevention Justice Alliance, Positive Women's Network, USA and the US Caucus of People Living with HIV. As a queer and trans person living with myalgic encephalomyelitis or ME/CFS, Long COVID and other complex chronic conditions, he writes and hosts conversations for The Cranky Queer Guide to Chronic Illness, sits on the board of ME Action and is a contributing member of the Patient-Led Research Collaborative which released the first comprehensive study on Long COVID. Next we have Fiona Lowenstein.

0:03:29.9 Fiona Lowenstein: Thanks for having me. My pronouns are they/them. I'm a white person with blonde hair, wearing a blue sweater vest, and I'm also in solidarity with the UMich grad students who are advocating for COVID protections, among other things.

0:03:45.1 AD: Thank you, Fiona. Fiona Lowenstein is an award-winning independent journalist, producer and speaker, covering health justice, wellness, culture, LGBTQ+ issues and more. Their work has appeared in the New York Times, Teen Vogue, The Guardian, and Business Insider, among other publications. Fiona is the founder of Body Politic, home of the original Long COVID support group. They are also the editor of the recently published anthology, *The Long COVID Survival Guide*, out in November 2022 from The Experiment. We're gonna put a link to that in our

chat. Next up, we have Netia McCray

0:04:31.2 Netia McCray: Hello, my name is Netia McCray. I am an African-American female with a short black afro, wearing wired headsets over the ear, and a blue or navy blue turtle neck as well as a navy blue headbands, and my pronouns are she/her, and I am here in solidarity with the UMichigan grad workers.

0:04:52.9 AD: Thanks, Netia. Netia McCray is an educator whose global non-profit organization, Mbadika has helped thousands bring their ideas to reality through leveraging STEM. For over 10 years, Netia has worked to demystify STEM in order to make it accessible to typically disadvantaged groups. As a March 2020 long hauler, she has witnessed first-hand the short and long-term devastation that Long COVID has brought to not only her community, but to communities worldwide. Netia believes knowledge is power and being able to obtain appropriate care and support starts with equitable access. Through her work with C-19 LAP, she utilizes her educational background to demystify Long COVID and recovery for communities like hers that shouldered the burden of the COVID pandemic. Next up, we have Lisa McCorkell.

0:05:45.4 Lisa McCorkell: Hi, I'm Lisa McCorkell. I use she/her pronouns, I'm a white woman with brown hair and a gray top on and blurred background, and I am also in solidarity with U of M grad workers.

0:05:57.9 AD: Thank you, Lisa. Lisa McCorkell is the co-founder of the Patient-led Research Collaborative or PLRC, a group of people with Long COVID who conduct research on Long COVID. She has presented PLRC's work to Congress, NIH, CDC, the President's COVID-19 Health Equity Task Force and more, and has co-authored several research papers and chapters on Long COVID. She is a policy expert with a background in social safety net, public health, labor policy, advocacy, writing and research. She has a Master's of Public Policy from UC Berkeley and a Bachelor of Arts and Political Science from UCLA. Next up, we have Dona Murphy.

0:06:47.8 Dona Murphy: Hi, I am Dona Murphy, and I am a Korean-American woman. My pronouns are she/her/ella. I have long, dark red hair at the moment, and I am wearing a grey shirt. I'm also here in solidarity with the University of Michigan grad student workers.

0:07:04.8 AD: Thank you, Dona. Dona Murphy is a neurologist, neuroscientist, historian of science, and community organizer. She has navigated local, state, federal and international partnerships across academia, government and health tech sectors, and rapid response and strategic mobilizations at the intersections of race, poverty and immigration. Her belief in the foundational democratic rights to help migration, public education and voting have informed her extensive grassroots activism and non-profit advocacy, and her run for her local school board in Texas. Her current project is a public benefit startup that marries her scientific and clinical expertise with a community organizing ethos to develop a digital diagnostic tie to culturally and language-specific content and community health worker access to help eliminate racialized health disparities and dementia. And last but not least, we have Chimère L. Smith.

0:08:07.3 Chimère L. Smith: Oh, don't worry, I've been going last my whole life with a last name that begins with an S. [laughter] My name is Chimère Smith, I'm a Black woman with a very, very low Caesar haircut. I am wearing a black sweater and behind me sits a China cabinet. I'm also wearing brownish reddish eye glasses or readers, and I'm also wearing medium-size hoop earrings,

and I definitely stand with the University of Michigan's grad students, being that we're here talking about Long COVID, it is so important that we all stand with anybody who wants to have COVID safety regulations and health regulations in the workplace. Thank you.

0:08:53.3 AD: Thank you so much, Chimère. And, in hoping for no little technical hiccups, I'm looking at our, 'cause I printed out this morning the interview bios, and for some reason it's... Yours is not on the website. Let me see if I can pull it up in my email.

0:09:10.3 CS: Okay. 'cause I know I sent it to you.

0:09:13.3 AD: You did, and it was just on the website. So we're working through them in live time, but here, I have it on my email, so we'll read it now.

0:09:19.5 CS: Okay. Sounds good. Thank you.

0:09:20.5 AD: Sure, of course, yeah, I wouldn't wanna leave that out. So suffering with the debilitating effects and symptoms of COVID-19 for nearly a year, Chimère L. Smith has had to learn the hard knocks of advocacy and healthcare. While seeking treatment and care, she experienced racism, sexism and dismissal by several medical professionals. Chimère boldly took matters into her own hands by challenging Baltimore hospitals for better comprehensive treatment for herself and other Black Long COVID patients in urban communities. She is an author, speaker, a highly requested panelist and thought leader who unapologetically shares her Long COVID journey, including balancing the effects of her disability emotionally, physically and financially. Chimère Smith has been featured on CBS, CNN, MSNBC, NPR, PBS, and in the Washington Post and the New York Times. She has written for Huffington Post Medium, the Long COVID Survival Guide, and She Knows. Thank you, Chimère.

0:10:21.6 AD: So today's focus will be hearing and learning from our panelists, but first, we want to provide a little background about the Global Feminisms Project for those who are new to it, and introduce everyone here to the Global Feminisms Project website, which houses the new interviews on Long COVID advocacy. The Global Feminisms Project was founded in 2002 by a collaborative group of Women's and Gender Studies faculty, including Abby Stewart, who's here with us in our audience today.

0:10:54.2 AD: The project collects interviews with feminist activists and scholars around the world, including sites in Brazil, China, Germany, India, Nicaragua, Nigeria, Poland, Russia and the United States. I'm happy to say that we continue to grow and new sites will be added soon. These interviews are then archived for use as research and teaching resources. In December 2021, we started adding to the United States collection with interviews focusing on Long COVID advocacy. Which was made possible by a grant from the University of Michigan Humanities Collaboratory. We'll now quickly demonstrate how to navigate our site. So you can go up to interviews and come down depending on the site you want, but in this case, we'll go to the United States site page. You move over to the right to find our interviews. Each site is contextualized with a brief introduction, and then the interviews are listed alphabetically, we have each interviewee... With each interview, we have their bio and a photo. You can also navigate the site through keywords. So if you press, for example, community activism under the first interview or active, either one, thanks Zoe. You'll be able to see interviews across site that all touch on the keyword community activism, and then if we go back, you can see that we have carefully annotated transcripts of each interview, thanks to the

hard work of our staff at Global Feminisms Project.

0:12:43.9 AD: You can also press YouTube video to see the full recording of our interviews, as well as name pronunciation. Thank you so much, Zoe. That's really helpful. So as we'll hear today, the patient coined term, Long COVID, describes a range of often disabling symptoms that persist after the acute phase of COVID-19 is over. Since the onset of the COVID-19 pandemic in January of 2020, Long COVID's recognition has been catalyzed by the efforts of Long COVID patients who have mobilized grassroots advocacy organizations around the world. Across the seven interviews we collected on Long COVID advocacy, three primary themes emerged: self-care or rest, collective care, and disability justice. So we're now going to show short clips from three different interviews that illustrate these themes, followed by responses from three other panelists. The first clip we're gonna show is from Chimère Smith's interview about self-care and rest.

[pause]

0:14:02.3 AD: Zoe that audio isn't on.

0:14:11.2 CS: In order for me to be present, I have to rest. There are days everywhere, they're days at a time when I have to... This couch is Chimmy's couch. This couch will transfer into my bed because I understand that in order to move a little bit, talk a lot, whatever it is I have to do on any given day, when I can do it, right? It's contingent upon when I can do it and if I can do it. I have to rest. Resting has to become... Resting has become... Let me say it like this, has become my primary job. And it's interesting as a woman, because most of us, and especially as I look at how our country operates, I was talking to somebody the other day who said, "Oh my goodness, I miss working 100 hours per week." And I thought about my life as a teacher, and I would come in to the school building at 6:30 AM. I wouldn't leave until 6:30 PM. I would stay as long as I could. I would be there on weekends, I would be planning lessons on Saturdays and Sundays, when I should have been out enjoying myself. I wasn't resting like I should have. I wasn't take... We don't practice that anyway. So what I've had to learn how to do is to make resting my number one priority. Even to the dismay of family, friends, loved ones, and people who just have that idea of going, going, going. I can't afford to do that, because if I go, go, go, go, go, I will be sick for days, or weeks, or months at a time, and I don't want that.

0:16:18.4 AD: Thank you Zoe and thank you, Chimère. We're gonna turn now to Fiona to respond to that clip and also add to that with their own experiences.

0:16:27.6 FL: Well, Chimère always knows how to sum it up, [laughter] and those words really resonated with me. I mean, for those who aren't familiar, post-exertional malaise or post-exertional symptom exacerbation is in many ways a hallmark symptom of Long COVID, the experience of having your symptoms worsen or having one or more symptom worsen after mental or physical or emotional exertion is quite common. And so I think many of us have developed techniques for rest and pacing that for me was very crucial in my early stage of recovery, but it is still something that I rely on to manage the symptoms that I live with today. But I think it's important to note that being aware of this and being able to enact it are two different things, and Chimère touches on that in terms of the social pressures of what is expected of us by our family and our friends and our co-workers, if we're still working in some sense, and also what's expected of us by society. We live in a society in which productivity is often tied to worth and our value is often measured by how much we produce as a worker, and that's been, I think, for me, a very difficult thing to untangle on the

days that I'm not able to produce or not able to work.

0:17:52.1 FL: I also think it's important to note that Long COVID patients have unequal access to rest and pacing. In my own case, I live with a partner who takes on a larger share of our household chores. I don't take care of any dependents. I have a job that allows me to work from home and flexible hours, these are things that make it a lot easier for me to take a break in the middle of the day or pace my activities versus someone who doesn't have those privileges. At the same time, folks who face greater structural barriers to accessing rest, also often come from communities where there is, I think, very real messaging that you have to work twice as hard to achieve the same success as a white economically privileged cisgender man, for example. And this messaging is true in a lot of cases, it's also sometimes not true. I'm just thinking about the... There's no room in Lean In feminism for rest and pacing. There are certain narratives that I think we do have to start to push back on, and I wanna mention Karla Monterroso here wrote a great chapter in the Long COVID survival guide on what it's like to be navigating the nexus of just the reality of growing up in an immigrant family in the United States, low income family, and getting that messaging and knowing it's very real, and then developing an illness where you really do have to rest and pace.

0:19:20.0 FL: And the last thing I'll say is that the other thing that makes this very difficult is that accessing care and accessing support for Long COVID is in and of itself exertion. A lot of the time leaving the house to go to a doctor's visit or filling out the paperwork that's involved in trying to access benefits and so something that I've heard advocates say which I think is really helpful is to kind of know that it's also not a failure to take a break from that stuff if you need to and that it's all a balancing act. Figuring out whether it's worth pursuing that care at the detriment of maybe having a post-exertion malaise crash versus getting the care that might be really helpful in the long term. So those are my thoughts but definitely curious to hear others.

0:20:09.6 AD: Thank you so much Fiona. That was really illuminating. We're gonna move on to the second clip and this is from Lisa McCorkle's interview about collective care and mutual aid in the context of work which I think has some really nice segues to what we've just heard.

0:20:34.4 LM: So in our survey we found that two-thirds of our respondents were either completely unable to work or had to reduce their hours. I think that a lot of it based off of, from what we've heard from patients and what we've experienced ourselves, is not that people are actually completely unable to work but they're not receiving the accommodations that they need to be able to work in our current society and the really harsh demands and very strict time frame that society has set up work. I think that's one of the best things about PLRC is that we communicate largely asynchronously so whenever we try to limit meetings as much as possible so people don't have to be feeling well and be expected to feel well enough for a phone call all at the same time. So you participate when you're able to. Having long deadlines, not having short turnaround times, allowing people to work in the middle of the night if they need to, and just really focusing on what are people's access needs in order to participate and trying to meet those as best as possible.

0:22:01.2 LM: And so that's how we've run our organization and we have done a lot over the last two years. It's not that, I think we have created this model of work that is where people can contribute when they're able to. And we have this really amazing work product and we're able to make a lot of change in the world but it's on a different timeline and using different structures than what most of the capitalist society adheres to and thinks is required. And yeah we'll have a lot of our volunteers will go through relapses, will be crashed for weeks, and we never want people to

work through that. Health is the priority. That's the priority for us is people's well-being and unfortunately that's not the priority of most of the society. It's not wellbeing it's productivity. And for some reason there's a disconnect between seeing that with the well-being you then get productivity and... Yeah so I think as more people develop Long COVID unfortunately it's just gonna be necessary for employers to be more accommodating. So there's a benefit to all of this, if I can say it's a benefit. But right now we're looking at 7.5% of all adults in the US have Long COVID right now. That's a huge percentage of working people that will need these accommodations or else we're gonna have a significant portion of our workforce missing.

0:24:12.5 LM: So yeah I think getting through that radical rest is important. Should be part of people's day-to-day work schedule if they need it. It's just going to be really crucial for our economy to stay afloat, for people to continue to take care of themselves financially, take care of their families. Just understanding that concept and understanding it's benefit is gonna be really really critical.

0:24:54.4 AD: Thank you, Lisa. Just a note that we have comments in chat from Chimère in responding live time to watching Lisa's clip. Accessing care is the most tiresome part it seems and many of us had to quickly transform our lives after COVID so that our work is more independent to keep ourselves safe and to honor what our bodies and minds need to survive and make a living. I see in Q and A someone mentioned that there's a problem with captions, so we'll try to make sure that stays consistent. Dona Murphy would you like to now respond to Lisa's clip and build on with anything you might be able to share?

0:25:35.8 DM: Sure so on the subject of mutual aid and collective Ccare in Long COVID, I think it's useful to think about disability as transient, potentially transient, graded, fluctuating, sometimes invisible. And if we use disability as a framework for not just reacting to but building persistence that accommodate our holistic needs as individuals and as a society, then I think our lives would be so much more humane. And furthermore, I think it would create the space then for us to not just survive but to thrive all of us with our own distinct needs. And when we think about the broader implications of Long COVID and how it can inform how we change systems, there are so many ways in which that can happen. We can start with how we as individuals can leverage our own personal experiences to transform the world around us. So for me, my own personal experience with Long COVID-related disability has informed this public benefit company that I'm now building which has emerged actually right in the middle of my Long COVID experience and that's this company called Prognosis.

0:26:50.4 DM: It has informed both the why and the how of what I'm building. So just as a brief description, it's basically a company that offers a platform for early dementia screening and culturally tailored and language-specific counsel with contents and communities that are created by caregivers of dementia patients. And through the advocacy that I've done in the past which is very heavily intersected with health and or was explicitly about health.

0:27:20.5 DM: I've been really involved. That has actually informed also this current project. And it's clear, it's become clear to me through that advocacy in the current project that I've undertaken, that those of us who are most proximal to the problems best know how to navigate those problems. And for me personally, I have my own concerns not just about Long COVID, but Long COVID as it pertains to dementia. Actually now we're learning more and I think we will continue to discover more as time lapses about this connection, and I already have actually a very high risk for dementia

with a history of a brain infection prior to Long COVID, so I have a 31-fold risk of dementia. So that's my personal... I guess I'm personally very invested in this and... yeah and as I said, that's outside of even the neurological symptoms associated with Long COVID and how that may or may not be related to the future risk for dementia as well. Like Lisa mentioned for PLRC, the ways in which we are accommodating the needs in the company that we are building in terms of the content creators and caregivers the both and I'm one of those people as well.

0:28:39.9 DM: The platforms and the processes that we put in place for us to collaborate, the expectations that we have in terms of timelines, I think is dramatically different for most companies because we care about the care recipients as well as the caregiver needs. And I think ultimately we also center the collective well-being and the work that we're doing both inside and outside of our company, we fundamentally understand all of these things to be connected. Yeah.

0:29:11.2 AD: Thank you Dona for sharing these thoughts. I really appreciate it. We're gonna move on to our third clip and this one that we'll show you is from JD David's interview about disability justice. And a reminder too as we go if you have questions that come up, please put them in the Q and A, and we'll answer them at the end.

0:29:38.3 JD: The reality is we need to have liberatory movements that aren't endurance tests and we need to have liberatory movements that are deeply infused with, suffused... I don't know the word, surrounded by disability justice. And even if it wasn't the truth that disability justice, which says that all bodies are worthy and all of us contribute in ways whether they're recognized by capital or not, that are valuable and all of us are deserving of circumstances to contribute the ways that are good for our bodies and our spirits. We extra need that for long COVID because people could be cementing in place lifelong illness and disability. The other thing though I think we need is to more and more support for what it means to live with life-long illness disability and as much support as possible for people to be as well as possible in any state of mind body or spirit and the biggest challenge I think across the board for many people with long COVID... And I should say I'm often not speaking of the most severe because it's a whole level of intensity that I can't speak for or characterize and that often gets left out.

0:31:13.7 JD: Whether you're talking about severe or very severe ME Long COVID, so I wanna make it clear I'm not doing that. For those of us who have intermittent or mild or moderate presentations like the biggest challenge is income and being able to provide for ourselves and our families to have a place to live, food to eat and so without... I think one of the real things we should be winning from this pandemic that we've needed all along is universal basic income. That's the treatment we need for so much of Long COVID, in a way that would be truly inclusive of all people regardless of race, location, gender, immigration status, but to have the basics of our life covered so we have the option to rest. Without that, I fear that we end up blaming people for their own recovery or lack of recovery. It's seen as, if you've gotten better it's because you've done the right things and you're good and if you're not getting better it's because you're not doing self-care and you're bad and you've done something wrong and I think we have a really... The importance of an accountable and principled Long COVID movement rooted in disability justice is huge as we look at what's gonna unroll in the next couple of years.

0:32:57.3 AD: Thank you, JD and we're gonna turn it over to Netia to respond to that clip and also add any other thoughts that you wanna share.

0:33:08.4 NM: Thank you so much. I think JD was right on the money because there's so much overlap between the disability justice movement, the racial justice movement, the feminism movement, all of these movements, including LGBTQ, anyone who is considered a minority in this country, there is so much overlap with the disability advocacy movement and what I mean by that is I am obviously an African-American or a Black female or I present as such and one of the things you're taught very young is that when you walk outside of your house or whatever you call home and you leave your family who understands you for you. And family could be blood relatives it's whoever you consider who understands you... The world outside of your home is always gonna question if you really...

0:34:02.6 NM: And they will always question whether or not you deserve to have X, Y, and Z. And I think that framework that has been the core of America's foundation is what has prevented us from doing the work that needs to be done in order to address things like Long COVID. Because as JD was mentioning the number one solution right now, especially for those with mild to moderate long COVID, is the safety net that income or universal basic income provides and guaranteed healthcare access. Almost everyone I know who suffers more a chronic illness, the only reason they are continuing to push and break their bodies knowing that participating in the workforce in the way that we have it structured that people are forced to participate is causing them to decrease their life expectancy as well as their quality of life.

0:34:55.6 NM: I have as the expectation of the zip code I live in, regardless of my educational background, regardless of the work that I do, regardless of my privilege, I am still in a zip code that the average lifespan of an African-American female or male is 50 years of age. And all the time I hear the reason why that life expectancy is so short compared to if you take a three-minute bus ride to the next zip code which would be downtown Boston in the South End or you're going into Beacon Hill which the average age is 83. So almost a 33-year difference which is almost the age I am right now and I know how much I've done in that time. When I've asked why such a discrepancy. I'm always told, "Oh it's their lack of choosing healthy food options? It's their lack of exercise." A quick walk through my neighborhood will show you there is no grocery store within a 20-minute walking distance let alone the 20-minute walk if you're able to do a very fast pace doesn't involve a healthy grocery store option. It's a Save a Lot, which I hate to be this person, but it's not a fresh food option, and on top of that there's hills, I was not disabled at the time before Long COVID...

0:36:15.3 NM: And at that moment I could barely get up the hill. I had to take the bus. Which was a financial privilege that I had, but I couldn't imagine my neighbors being able to do that. They had to rely on community care because, as I mentioned earlier, everyone in your home recognizes who you are and doesn't question the fact that you need disability aids, a safety net and support in order to contribute your best to society. They understand you need those things, but the world outside whether it's the healthcare settings, whether it's police, whether it's the justice system, whether it's social security, where it's any governmental entity for-profit, non-profit entity doesn't see it that way. And so I completely agree with JD's point on that. I would like to wrap up my thoughts with this quote, you don't look into somebody else's bowl to see how much they have, you look in their bowl to see if they have enough. Another core issue we're facing is that people feel, they're getting the short end of the stick. And nobody wants to feel that way and I think a lot of individuals look at Long COVID as, "Oh, you're tired."

0:37:27.9 NM: "Well, I'm tired too. I have four kids. What are you tired about," or "Oh you don't

wanna go in office... Well, I have to go in office four days a week so why do you get to work from home? Oh, because you get dizzy going up some stairs that's why you all of a sudden need to get SSDI... Well I get dizzy all the time you don't see me being able to sit at home and get the government check." And all of these thought processes are centering on nobody wants to be the sucker. And I'm hoping that Long COVID and the high prevalence of Long COVID not only in my community but now communities across America which wasn't the case when I first got sick in March of 2020, everyone is starting to realize that if 20% of our population is gonna be hit with this and we're gonna allow multiple COVID infections as we decide to end the public health emergency on COVID, as pretty soon one of those bullets I like to say is gonna hit someone you love or care about or maybe even hit you and instead of being concerned about getting the short end of the stick, maybe we should change our framework on that and focus on...

0:38:39.0 NM: "If I do get the short end of the stick, wouldn't I want someone to make sure that I'm good? Wouldn't I want my community to support me and my needs and make sure my family and loved ones are taken care of, instead of seeing all of that crumble down?" And that's what we've been working at C-19 LAP, is helping to change that framework. And I'll say my very last point, and why this overlaps with so many advocacy movement, disability justice movements, etcetera, is that the short end of the stick is a symptom of a larger problem, and that's nobody wants to add or shoulder more of the burden than what they're already going through. Back in June of 2020, when we were experiencing the George Floyd protests and we were still in the midst of the pandemic emergency, and everyone was scared what the future of America would look like, I was still battling with mild to moderate, Long COVID, I didn't know in it within a year, my mild to moderate Long COVID would become moderate to severe, I would become that bed-bound woman who had the mask, the ear muffs, and couldn't let light in and who couldn't talk for days on end or walk or take care of herself.

0:39:57.6 NM: People look at me now and see me as a success story because I'm able to talk to you all on this webinar, and they see me as a symptom of, "Well, obviously, Long COVID can't be that bad. Look at her. She was able to get over it. She's able to contribute to society. That's all we're asking from the Long COVID Community." And I like to say, I am not a success story, I am evidence of systemic failures of our systems, I am only here because the Black community has already understood something, the disability community has already understood something, the LGBTQ community has already understood something. Without community care creating the safety nets that we as a nation haven't already discovered is a necessity and a right that should be shared by all Americans and not those who've been born into privilege, we cannot survive. I am of a small percentage that I can count on one hand, who has been able to move from moderate to severe Long COVID to mild, moderate Long COVID. I am able to give voice to those who have sat in their beds and have been told that it's a psychosomatic disease, and they just don't want to work and they're lazy.

0:41:17.1 NM: It was similar to the same things I heard that my classmates in my high school just were failing classes because they were lazy Black children, versus their teachers were purposely failing them. Or the arguments I would hear when I would have a friend who was sexually assaulted and everyone would say, "Well, didn't she know wearing pants at night was the reason she was assaulted?" And so I'll wrap up my thoughts responding to JD with this quote, "The stakes for you shouldering this burden unlike for me isn't life or death, if the burden is too heavy for you, then help us fix the system. If the system cannot be fixed, help us dismantle it in order to ensure equal opportunity to life, liberty, and the pursuit of happiness." That's not us asking for revenge, that is us

demanding active recognition of our constitutional right to equal protection and the pursuit of happiness under the law. That is justice. That quote was from June 2020 from me in the Boston Globe when I thought I was gonna die. That is what your neighbors, if you're not afflicted with Long COVID have been experiencing whether since 2020 or since this latest Omicron wave. Long COVID Justice is disability justice, is racial justice, is feminist justice, is LGBTQ justice. And that's what our focus needs to be moving forward. So thank you.

0:42:57.2 AD: Thank you so much, Netia. Thank you all for your insights and your thoughts. Before we move to some of the audience questions, did anyone have thoughts that they wanted to add?

0:43:13.5 CS: Yes, I do wanna say something. Wonderful Netia, as always. I think that just really puts a cap on it, and I think... I do not wanna make this conversation political, but I do wanna say that all of these movements that JD and Nisha talked about are an essential reason why there should be no type of erasure in this country. Not one looking from a feminist lens, from being Black or a person of color, from being disabled or having Long COVID or any other chronic illness or invisible illness or it being any type of other that we tend to look down on, although the... While I'm not always very keen to the foundations of our country, we said that we wanted others. We said that we wanted a smorgasbord of people doing different things. And so all of what we said today is essentially why no part of history can go unnoticed and why no part of history can afford to be erased, because when you teach people their history, you teach them how to act in ways that we have all acted, including you, Abby.

0:44:39.1 CS: I was listening to you and listening to my video and our videos brought back the fact that when you listen, you have a very compassionate way in which you listen, and it almost reminded me of talking to a sister girl and Netia, you understand what I'm saying? It's like when we listen to each other, we're like, "Mm-hmm. Mm-hmm. Hmm." And I said, I love talking to you because of that, because I felt heard and respected. And so when we think about what all of this means, this global movement that you have spearheaded and others have as well, this is why history in any form cannot be erased. Because for instance, if it's already being said that we want to erase Black history and LGBTQIA+ history, then guess what, in about three to five years, they're gonna try to erase Long COVID history, or they may try to erase more HIV history or more feminist history, and so we can't afford that. So I think it's been good that we've all seen our clips and we've all been able to examine them and speak to them, because it explains even further why history in our country and everywhere really, since we're talking about a global movement, it's so vital so that people who are educated, not just going to college, but people who know better do better.

0:46:10.0 CS: And when you know the tenets and the fundamentals of how to fight for your life and how to fight for what you and other people need, you can only say that that's because of history, the only reason that all of us knew how to fight was because we were taught to do that in very different ways, but it's all become a more collective connective movement because of what history has shown us for the good, bad, and the evil and the indifferent. So thank you, I appreciate that.

0:46:41.3 AD: Thank you, Chimère, that was really powerful. And I think this is a good time to turn to some of the questions that have come in, there were questions sent in prior to the webinar, and maybe I'll read the first one and see if anyone wants to take that one. One question that we got was, a lot of patients are educating providers about Long COVID, has anyone created a continuing medical education course that can keep providers up-to-date? Is anyone working on this? I don't

know if anyone feels like they can answer that.

0:47:15.9 JD: There's different things going on, but one thing I'll point out is called Project ECHO E-C-H-O, which is a, it's both a research study and the training program for providers looking to see how to extend the excellent care through publicly funded health systems. So there's specialist doctors who work with doctors at a federally qualified health center in San Diego, and then they're comparing the care to see how people do who have Long COVID or other fatigue illnesses. So as part of that, there's training and monthly webinars for both the public and for providers, and Project ECHO is a methodology that's been successful in extending care to more people with HIV and with hepatitis, so I'm hopeful that it will be effective as well with Long COVID, particularly because they're working with patient experts, like myself and several of us have been involved, and we sit alongside the providers on these panels to train the other providers about what to do.

0:48:19.3 AD: Thank you, JD, that was really helpful. Another question that came in, how do we start advocating the government and parliament to acknowledge Long COVID and all needed supports? Anyone?

0:48:40.6 DM: I'll speak to this maybe a little bit. You can do this like at all levels of government, I can speak from the US context, but I'm sure there are analogs in other countries. So at the simplest level, you can do it at the level of your school board. Which was... We recognize now it became very, very important during COVID because it was a site of community transmission, we have a lot of children together, so we had a lot of community spread that way. So that's one place you can go to make sure that you have protections in place, not just for this pandemic, but future pandemics too. And then also like your city council, your Board of Supervisors for your county or your county commissioner's court, it's called in some places, and then your state legislatures, your federal government also obviously, so Congress and whatnot but I think it's most... For most people who are not already very politically engaged, it makes the most sense to start very local because those folks have the most control over what happens in your day-to-day life.

0:49:47.8 FL: I would also add, and I think this plays into a little bit of a question of what the media is leaving out, that advocating around Long COVID also means trying to prevent future cases of Long COVID, and I think increasingly there is a missing link between caring about Long COVID and caring about mitigating COVID infection, and I think it is politically less popular to care about mitigating COVID infection and mitigation efforts like testing and masks and vaccines and access to things like Paxlovid, but it is illogical to care about Long COVID and not care about the first thing.

0:50:24.1 FL: So when we talk about advocating with local elected officials around Long COVID, we're also talking about how do you protect your communities from contracting COVID in the first place? Because that is currently the only known way to prevent Long COVID from developing. While we know Paxlovid and vaccines may help to reduce the chances of Long COVID developing, the only way to prevent it is to prevent someone from developing COVID in the first place.

0:50:50.3 CS: And Abby, I'll also this about how to advocate as I think as Dona mentioned, it can start on such a small level, I, prior to my advocacy and becoming ill, never would have been this confrontational about my healthcare and the healthcare people around me, I was always like... I would go along to get along because culturally, that's what I've been taught as a Black woman, is not to make a fuss to think, "Okay, you have this good job where you're a part of the middle class

now, and so the worst thing that you could do is to speak out against anything that could cause any type of revenge or retribution that could affect my livelihood." But what I started to do was... The smallest thing is I started to ask doctors questions, I started to ask them to put what they chose to do or not to do in my medical file, on my medical reports. I started to make them say in my medical reports that I suspected that I had a case of Long COVID, even if they did not. And so things like that make a huge difference in how advocacy starts because it's not so... People think that fighting for justice, disability justice, racial justice is all about fighting and being confrontational and argumentative, it doesn't have to always be that, it can be simply making requests, making demands without ever leaving your chair or without getting in somebody's face.

0:52:39.0 CS: And so I did those little things to show how invested I was in my care and the care of other people. I also started to speak about other people who were experiencing certain things, and I think that's what started the ball rolling from me, and it can start the ball rolling for other people as well. Just making people aware, the more you make doctors aware, the more you make the politicians aware, the more you make your family aware, then that is how advocacy can start. Very simple. It takes a very small fire to light a whole room up.

0:53:14.8 JD: Yeah, I would add that... Thank you everybody for what you contributed, that being a successful advocate comes from knowing ourselves, knowing our skills and qualities and what we care about the most, and putting that into service alongside others. And alongside others could be two or three friends, or could be a activist group with millions of people, but what's happening now is we are being misinformed as to be considered a vast minority, when in fact, there's a vast majority of people who are at risk of long-term complications of COVID and who are at risk of more severe acute COVID. We're actually the majority. So the changing the narrative that's going on now starts by conversations with those among us, but also being able to look at opportunities to take the public mic for those who are ready to be or like to be confrontational, let it out. Be angry. You have the right to be angry. And what's happening now is not an accident, it's purposeful. As the pandemic was approaching the United States, we were told by the news that it was gonna be okay because only sick and old people were gonna die. We've been considered expendable since long before COVID-19. In order to change this, we need to change it for everybody. So now is the time to use whatever mechanism you have in hand to take action, to speak out, to write out, to put up a banner, to disrupt however and whenever you can, and for those around you who love you, to ask them to do so as well.

0:54:56.5 NM: I would say excellent points, and I'm gonna drive home that point a little further, and that right now, Long COVID patients or those who know and have a term for what they've experienced, whether they were a chronic disease or illness patient before, they got Long COVID or Long COVID is their first brush with chronic illness and living with it, that community right now is in complete fear of what the end of the public health emergency will look like. I can speak personally, that even I am being pressured to the point that I'm having to make decisions of, "I've already sacrificed so much of my life and fought tooth and nail and come back from the brink of death to be here, and now I have to look at a future." And not a future, which is years ahead, I am talking about two months ahead of what is it going to take for me to maintain the health I fought so hard to regain? While health is not guaranteed, it is something you cannot pay for in this country, and it is something that I have spent and have asked others to contribute and to support, and they do not have the funds or the ability to make miracles happen twice.

0:56:15.1 NM: One of the things we as a country need to decide, if we're gonna continue to move

forward with same old, same-old, what does that mean for the communities who gave the sacrifice, especially those who are dismissed because they were elderly or they were sick as, "Oh, they're already disabled. How much more do they have to lose?" Well, they don't have a lot to lose, so you're asking them to lose everything for what you foresee as a future that you don't want to change, and that inflexibility is where we're gonna come at a cross-roads. I understand everyone is in their own situation, and what we see in the world outside of our walls is a calm, like 2019. But it's not calm. And one of the best ways I've seen my patient advocacy as of late, is having those private conversations when people ask me, "Why are you still wearing a mask? What are you scared of?" And I go, "Well, why do you use hand sanitizer?" And they go, "Oh, I don't wanna get sick. I've been sick for the past six months, and I'm just trying real hard not to get sick." And what I love about science communication and advocacy and how all these things overlap, is I can be the scientist in the 1700s who explained thunder to people for the first time and allowed for them to realize that chaos of a thunderstorm is not chaotic, it's scientific, there's meaning, there's a reason. And once people find out why things are happening, the chaotic nature of their lives comes down.

0:57:51.5 NM: Over the next couple of months, what anyone on this call can do is advocate for those who cannot advocate for themselves. You've heard all of us mention that U grad students, the U Mich grad students, that's a simple thing you can do to help keep the health of those workers intact. A lot of people have been sick the past couple of months and have no idea why they've been sick. I have more friends who've had aneurysm, heart attacks, strokes and cancer diagnoses in the last six months than in my entire existence. My mother, who was 55, does not understand what is going on with my generation. People are living chaotic lives, and the only thing they're holding on to is the sense of normal they had in 2019. We can help them find the calmness in this chaos. And that's how we can start this work.

0:58:48.6 AD: Thank you so much, Netia, all of you, for your insights and your thought and your care, for being here today, we are one minute to go at time. I just want to thank again, everyone who worked to make this happen. If you're not already on the Global Feminism's Project listserv and are interested in joining, Heidi is putting up a sign-a link in the chat now. We appreciate you. Thank you, thank you for being here. And again, if you had to leave and miss some of the recording, we will send that to all registered attendees and they'll be on our website. So take care.

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