

**GLOBAL FEMINISMS  
COMPARATIVE CASE STUDIES OF  
WOMEN'S AND GENDER ACTIVISM  
AND SCHOLARSHIP**

**SITE: UNITED STATES**

**Transcript of Teresa Akintonwa  
Interviewer: Abigail Dumes**

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**Abigail Dumes** is a medical and cultural anthropologist and an assistant professor in the Department of Women's and Gender Studies at the University of Michigan. Dumes received her PhD in sociocultural anthropology from Yale University, and her first book, *Divided Bodies: Lyme Disease, Contested Illness, and Evidence-Based Medicine*, was published by Duke University Press (2020). Her ongoing research explores the relationship among gender, contested illness, infectious disease, and environmental risk in the United States; she is working on a new project on Long COVID.

**Teresa Tindle Akintonwa** has been an Educator for over 25 years with extensive experience in Instruction and Corporate Training. Since becoming a Long Hauler after her initial covid infection in February 2020 she founded the Black Covid-19 Survivors Alliance which was first an online Patient-support group. It has since evolved into activism and advocacy aimed at helping African-Americans overcome the misinformation and social stigma of Covid and Medical Research involvement. As President of Black Covid Survivors Alliance she now collaborates with various organizations to increase Health Equity through Health Coaching, research participant recruitment, and DEI advisement to Research organizations.

**Abigail Dumes: Hi! My name is Abby Dumes. My pronouns are she/her. I'm a white woman with an orange floral print shirt, and bird-shaped turquoise earrings. I have brown hair in a braid; over my left shoulder is a red framed painting, and to my right are bookshelves.**

Teresa Akintonwa: I'm Teresa Akintonwa, and I am an African American woman. I'm wearing a red blouse with um—a feather on it, and I'm in a room that is blurred in the background.

**AD: Thank you so much. Thank you so much for being here, and for being willing to share your story with the Global Feminisms Project. I'm going to briefly introduce you and then we'll move on to our questions. Teresa Tindle Akintonwa has been an educator for over 25 years with extensive experience in instruction and corporate training. Since becoming a Long Hauler<sup>1</sup> after her initial COVID infection in February 2020, she founded the Black COVID-19 Survivors Alliance,<sup>2</sup> which was first an online patient support group. It has since evolved into activism and advocacy aimed at helping African Americans overcome the misinformation and social stigma of COVID and medical research involvement. As President of the Black COVID-19 Survivors Alliance, she now collaborates with various organizations to increase health equity through health coaching, research participant recruitment, and DEI<sup>3</sup> advisement to research organizations. So I thought we'd start with where your story begins, as you think about where you are today; I'd like to get a sense of your journey up until this point and what brought you here.**

TA: Okay, well, the first thing I want to say is that—Is really my journey has been one of um—forced courage. And um—you know, of course that like, as you said, I started off in my career was an education and training. One thing I will kind of give you some background on is that I grew up in Chicago inner city Chicago on the Southside<sup>4</sup> in the 1990s. And during that time there was a lot of transition, and many neighborhoods were being affected by you

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<sup>1</sup> Long Haulers are those who endure long post-COVID conditions. "Long covid: Long-term effects of COVID-19." Johns Hopkins Medicine. <https://www.hopkinsmedicine.org/health/conditions-and-diseases/coronavirus/covid-long-haulers-long-term-effects-of-covid19> (accessed October 4, 2022).

<sup>2</sup> The Black COVID-19 Survivors Alliance is a collective group of Black and African-American COVID survivors advocating for patient equality and support. "Survivor Stories." Black Covid Survivors. <https://bcsalliance.org/> (accessed November 1, 2022).

<sup>3</sup> *DEI stands for Diversity, Equity, and Inclusion*

<sup>4</sup> Southside Chicago is an area located to the south of Chicago, a large metropolitan city in the US State of Illinois. "South Side, Chicago." Wikipedia. [https://en.wikipedia.org/wiki/South\\_Side,\\_Chicago](https://en.wikipedia.org/wiki/South_Side,_Chicago) (accessed August 28, 2022).

know the drug epidemic<sup>5</sup> and so forth. And I think a lot of that is kind of what fed into who I am today, in the aspect of oftentimes feeling, you know, like, I was on the outskirts of, you know, a greater and more powerful society. Um—both as a woman, and also being, you know, socioeconomically different from—you know—mainstream society. But I’m a wife, I’m a mother, you know—I’m an income earner for my household. And, you know—the summer of 2020 really changed so many of our lives. It wasn't just, you know, the onset of COVID, you know, in February, March. But, it also was the social unrest<sup>6</sup> that we had that was a huge part of even why I started Black COVID Survivors.

**AD: Interesting.**

TA: Yeah.

**AD: Can you talk a little bit more maybe about what happened February 2020 on?**

TA: Sure.

**AD: Experience—**

TA: So, right. So, you know—I’m working and just—you know, I was working for a franchise<sup>7</sup> in which I, you know, opened up franchises and—and kind of did business development, and so forth at that time. And I was the only—for a long time, I was the only Black person in my office. Up until we had changed some leadership, but there had been some—some discord, you know—per typical office politics. But it seemed to kind of get aligned racially, and that was something I think that really contributed to me, you know, not looking out for myself as much as I should have. Wanting to, you know, show myself to be a part of the team, you know—and to be there for everyone else. Um—and not be—you know—exclusionary. And so, I continued to work when—you know—my conscious told me, you know—there's—there's a sickness going around right now, you know. I didn't want to be the one person, especially the Black one [laughs], who didn't show up to work or—you know—declined to go see customers and things of that nature. And so, um—I

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<sup>5</sup> The drug epidemic refers to the increasing waves of prescribed opioid and drug overdose deaths in the U.S. that initiated in the 1990s. “Understanding the Epidemic.” Centers for Disease Control and Prevention. <https://www.cdc.gov/drugoverdose/epidemic/index.html> (accessed October 4, 2022).

<sup>6</sup> Social unrest, or civil disorders, refers to a situation of massive public resistance acts, including demonstration, strikes, etc. “Social Unrest.” Emergency Management. <https://www.seattle.gov/emergency-management/hazards/social-unrest> (accessed October 4, 2022).

<sup>7</sup> A franchise is a type of business that involves selling licenses to external parties to use one’s branding and products. Hayes, Adam. “Understanding How a Franchise Works.” Investopedia. <https://www.investopedia.com/terms/f/franchise.asp> (accessed October 4, 2022).

would say that, yes, I was exposed to the virus initially just because of work. I traveled at the time; I went to customer sites, as well as traveling to different states in the southeast.

**AD: I see.**

TA: Yeah. And so, um, you know, it kind of began there. And one—one thing about COVID: when we first heard about it; we thought of victims, so-to-speak, or patients, as being people who were hospitalized, right? And people who had very visible signs of illness. And so, when I contracted my illness and continued to work, you know—there was a good degree of disbelief that I even had COVID, or that I was suffering from symptoms—long term symptoms of it. You know, because the questions often came like, “Oh, where were you hospitalized?” [laughs]. You know, “Did you have to go to the emergency room?” And you know if you're not hospitalized, you know, especially at the beginning of this, you know, um—you weren't really taken very seriously; you were just a paranoid citizen, you know? And unfortunately, I was greeted with that same kind of sentiment and interactions when I went to the emergency room. Um, at least twice at the—toward the beginning before—before summer even—I went to the emergency room about symptoms that I was having and, you know, they were really crowded back then. And the—the greeting that I received at the check-in desk was from a middle-aged white woman who just looked at me and she just scowled and she's like, “Ugh! Everybody around here thinks they have COVID.” And you know, “Everybody around here,” you know—she could have been meaning the emergency room, you know, but it was predominantly Black. And so was the—is the Community that this hospital was in. And you know, I was very—you know—makes you question yourself.

**AD: Right.**

TA: It's like, “Okay, well am I as sick as the others?” You know, “Should I be here trying to get resources that maybe someone more deserving”—you know—“should have access to?” And so just kind of as, you know, time went on, I realized, you know, or at least I began to feel that, you know, we're [brief pause] not being treated the same. And I had doubts about whether or not other people are—you know, being greeted the same way, right? When they express their concerns. The other thing also was not just along racial ethnic lines that I felt like there may have been some differences, but also with my gender.

**AD: Mm.**

AT: Um—when men go to the doctor—you know, I guess there's this—this narrative that, “Men don't like the doctor; they don't go.” If they show up—take 'em very, very seriously,

you know? And do all that you can to, you know, assist them and treat them while they're there; You may not get them back.

**AD: Mm-hmm.**

TA: And—and for women: the narrative is often that, you know, “We complain about everything,” and there's, “so much of our—our concerns and complaints are—you know they're minor, or they're just stress related,” you know. “We need anti-depressants,”<sup>8</sup> you know, to help, you know, “Counteract our hormone issues.” You know, there's just a lot of—of stereotype about women in general. And so, I felt like—I was—I was being affected by both racial lines—along the racial lines as well as gender lines as far as how seriously the health care facilities were taking me when, you know, I expressed my concerns: when I went in in person; even when I called, you know, my doctor's office.

**AD: Mm-hmm. Mm-hmm. And was there ever a point at which you felt like you found—validation or someone who took you seriously?**

TA: There really was—yeah [smiles]. Um—so, my primary care physician is a Black doctor. However, his PA (Physician's Assistant) was a young white woman. And, let me tell you—she was a lifesaver for me. I mean, during the time when—I almost get choked up thinking about it, but you know—during the time: think about this. Um—you know there's so much going on in society with the George Floyd<sup>9</sup> situation.

**AD: Are we moving into the summer? Is that—?**

TA: Right. So now we're kind of crawling, right? From the spring of 2020 to summer. And that's when I began to really realize that I was having Long COVID.<sup>10</sup> It was around probably April/May-ish that I began to realize like, “You know what? I'm suffering from things now that I didn't have before, and it wasn't actually a part of my acute illness.”<sup>11</sup> Um, the—

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<sup>8</sup> Anti-depressants are medicines used to mitigate depression and some other mental conditions. “Antidepressants: Types, side effects, uses, and effectiveness.” Medical News Today. <https://www.medicalnewstoday.com/articles/248320> (accessed October 4, 2022).

<sup>9</sup> George Floyd was a Black American who died of police brutality during an arrest in Minnesota, which catalyzed massive protests across the US. “George Floyd.” Wikipedia. [https://en.wikipedia.org/wiki/George\\_Floyd](https://en.wikipedia.org/wiki/George_Floyd) (accessed October 4, 2022).

<sup>10</sup> Long COVID refers to the prolonged duration of COVID impacts after the infection. “Long COVID.” Centers for Disease Control and Prevention. <https://www.cdc.gov/coronavirus/2019-ncov/long-term-effects/index.html> (accessed November 1, 2022).

<sup>11</sup> Acute illness refers to abrupt yet short-lasting symptoms. “Chronic vs. Acute Medical Conditions: What's the Difference?” The National Council on Aging. <https://www.ncoa.org/article/chronic-versus-acute-disease> (accessed October 4, 2022).

**AD: Hmm. Can you tell us a little bit—the difference between your acute symptoms and—**

TA: Sure.

**AD: —your Long COVID symptoms?**

TA: My acute symptoms was mostly uh—headaches. I had nonstop headaches, as well as fatigue, and I had a cough also. And this all seemed to get worse toward the evenings, I think, but it would also come on just very suddenly. Just as I'm speaking to you now. And then suddenly, I would just have onset of a coughing fit, you know? Very difficult to catch my breath—It's a very, very dry cough. As well as um—I was having some very serious um—cognitive—um problems—a lot of problems recalling of information. Um, finding words was very, very difficult oftentimes. You might hear, you know—you know this little meme on the Internet where it shows a snake—they call it a dangerous noodle or something [laughs heartily]. And it was almost to that degree, where some of the very basic words and terms and objects that you know should not have been difficult for me, you know, I would kind of look at them, or I have a picture in my head and—and I'm searching for—you know, what is the word for that, you know? And I began to realize like this is something else; this is not just distraction; this is not, you know, stress. Something's going on here. And so, going to the doctor—was one of my—going to see my primary care was um—started by that. Between that and the headaches is what kind of drove me in, during the time when, you know, again most offices were only doing telehealth visits.<sup>12</sup>

**AD: And did you have access to testing during your initial acute experience?**

TA: Absolutely not. Yeah, um—when I had it, I went in for testing and—and that was actually the first time I went in to get tested was the incident which I explained the woman was you know, talking to me, you know, very condescendingly. And if you didn't have a fever, a high grade fever, along with low oxygen, you were not prioritized. So, you know, once they triage you and saw that you're—you're basically, "There's nothing we can do." And that's what we were told, "Well, there's nothing I can do for you, honey." You know? We're just going to send you home and tell you to drink, where you know drink liquids and—and get rest. And you know, this is the south; I'm in Atlanta.<sup>13</sup> So, you know, for

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<sup>12</sup> Telehealth visit refers to a form of medical care in which, instead of in-person appointments, one talks to their provider virtually. "What is telehealth?" Telehealth.HHS.gov.

<https://telehealth.hhs.gov/patients/understanding-telehealth> (accessed October 4, 2022).

<sup>13</sup> Atlanta is the capital city of Georgia, a southeastern state in the US. "Atlanta." Wikipedia. <https://en.wikipedia.org/wiki/Atlanta> (accessed October 4, 2022).

someone to address you that way, you know, some, my Chicago instinct sometimes says, you know, “Who are you talking to like that?” [looks with both eyes to the side and eyebrows raise and laughs]. You know, and then, of course, my—my southern sensibility says, “Calm down. She calls everybody, ‘honey.’ She calls everybody ‘sweetie’”—you know? But, you know, I even felt that you know that that was—I don't know, I guess—I guess, a sign of her not taking me seriously. But testing wasn't available unless you had those—you met those two conditions or—or if you were a medical frontline worker. It was later confirmed for me, when I went in to have blood tests drawn and I asked them about antibodies.<sup>14</sup>

**AD: Hmm.**

TA: And, and I, you know, had kind of been watching the news enough to hear that, “Okay, if you had COVID—there really is a distinction between COVID-19 and the flu or any other type of coronavirus<sup>15</sup> that was known.” And so I went in and I asked to be tested and then it was confirmed. Yeah, by the antibodies tests that I did have COVID, or that I'd had COVID. And so, um—the difference—I gave you the symptoms—but as time went on the cough went away, but the headache remained. And it literally was every single day. I might have had you know, maybe 20 to 30 minutes time of relief here and there, but overall, it was every day. And even telling, you know, sharing this with, you know, my coworkers as we're all, you know, shifting and having to pivot from being a very “in your face” kind of a business operations to, you know, trying to translate things online. Um—that also, I think, was something—a barrier to people believing. Because they can't see you there in person, and so, you know, if—if I can't visibly see that you have a condition or handicap or sickness, it just doesn't exist [laughs]. You know, people can only believe as far as they can see, unfortunately, when it comes to illnesses. You know, and then you top it off, you know, I'm on camera so, like most of us, you know, I have on my shorts, but you know from the bust up, you know, I look great; I look camera ready, you know, etc.

**AD: Right.**

TA: You know, and I think that just kind of led to—continue, you know, that disbelief you know.

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<sup>14</sup> Antibody refers to a blood protein produced in response to any foreign substance entering the body. “Antibodies.” Cleveland Clinic. <https://my.clevelandclinic.org/health/body/22971-antibodies> (accessed October 4, 2022).

<sup>15</sup> A coronavirus is a type of virus that can cause respiratory illness. “What is Coronavirus?” John Hopkins Medicine. <https://www.hopkinsmedicine.org/health/conditions-and-diseases/coronavirus> (accessed October 5, 2022).

**AD: So, you were continuing to work throughout this?**

TA: I continued. Yes, I did. I pushed on; I continued to work. And unfortunately, you know, it really affected my—my work performance. It affected what I could do, you know? Um—I didn't even realize how much it was affecting me cognitively until I started getting feedback you know—that, you know, certain presentations weren't making sense, or it wasn't very cohesive. And I've always prided myself on being very well spoken and being a very confident speaker—and very succinct in my thought process and so forth. So, this was you know really different for me. And then to hear, “Okay, you're not just fumbling; you're not just fumbling from what you can tell. Other people also perceiving the same thing and even worse.” You know, that—that can take a—you know, it shakes your confidence.

**AD: Right.**

TA: It affects your esteem, especially, you know, as oftentimes we do—we identify ourselves by our, you know, what we do, right? For a living. It's not so much the—the money per se, but it's the contribution that we feel that we're making, right? The importance of our contribution to society is often wrapped in in what we do for a living. And so, you know, not being able to do that to the degree and competency, you know, that I was used to, you know, really shook me. And it also kind of further—I felt like it further validated some of the—the difficulty we were having socially in the office at that—at that time.

**AD: Mm-hmm. Interesting, so you seek care for the persistent symptoms, which are these headaches and this is met in a positive way clinically by the PA<sup>16</sup> that you mentioned, is that sort of—?**

TA: Right, right. So, my PA was--her name was Erin, and the first thing that I noticed when I went in to talk with her is that she listened. And when I say that she listened, I mean you know, she—I didn't feel a sense of, “Let's hurry you along, because I have another, you know, appointment.” Or, “you're being you know redundant” or, you know, trying to, you know, summarize things for me. You know, she really gave me the ability to—to think—to pause if I needed to, and to really just gather my thoughts. And honestly, I can't say that I've always—uh, you know, that's not how most visits go, you know? Even—even my Black doctor and he—I felt that he's always been a great doctor very sensitive to a lot of things. But she still listened in a way that I think was different, and I feel like that connection, you know, maybe it was because you know we were of the same gender, but for me it was a game changer. Because my previous experience had always been—you know, male doctors

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<sup>16</sup> PA stands for Physician Assistant

trying to assert that my conditions, “They're real, believe me. We believe you that they're there—but that it may have been psychosomatic.”<sup>17</sup> When—or that it was you know, “Depression-related or a stress-related.” And you know, “I’m going to give you this prescription, but I’m also going to refer you to behavioral health, you know to be seen there.” And—and that’s pretty much has—has been a very constant experience with the medical community that I’ve had going back to—back to my youth, when—when I was 20 years old and had my first child. And um—

**AD: That was going to be my next question: whether this preceded COVID or whether this was—?**

TA: Oh yeah, this treatment preceded COVID, but, believe it or not, it was a very long time before I even realized that I was being treated differently. Though um—from age 20, I was married at the time; I was in college, but I remember, I had a doctor who spoke to me about why I was there with my baby, and she says to me just very matter of factly, “Well, I know it's hard being a teen parent” you know? And, “But you need to—” And I’m like, “hold up, hold up, hold up.” And you know she even mentioned, you know me, “being a single mom”—just all these assumptions. And I did look quite young for my age, okay? But again, I’m a parent there with my child, and you're you know lashing out at me based on you thinking that A) you know, I’m a—was a teen parent, and I’m single you know—and you know that was kind of like my first little introduction there. Um that, “Okay, you do look a little young. Maybe you should, you know, present yourself a little differently [laughs]. You know, try to seem as mature as possible when you go into these appointments and so forth. Um—and it wasn't until, you know, I was probably, say—a good 10 years later or so. You know, somewhere around mid-2000s, 2006 or so, that I began to have these very overt experiences with male doctors, who were very frustrated with what they could not diagnose with me, you know? Um, and—you know my return, and them just not having answers; they lashed out at me for them not having answers.

**AD: Mm-hmm. Mm-hmm.**

TA: You know? And almost as—and oftentimes, you know—as if I was purposely, you know, causing myself illness. You know, I don't know what you want me to do! You know [laughs in disbelief]. Like these—like unbelievable kind of interactions that would only—you would only expect to come across you know, on—on TV in some drama, you know? But yeah, they're real. These very extreme interactions do exist; they happen all the time. I thought they happened because I was Black at first, you know? And then I began to realize

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<sup>17</sup> Psychosomatic Disorder refers to a mental condition correlated with some physical symptoms that can't be medically diagnosed. “Psychosomatic Disorder.” Cleveland Clinic. <https://my.clevelandclinic.org/health/diseases/21521-psychosomatic-disorder> (accessed October 6, 2022).

that “Girl, your gender. You just being a woman is why they're doing this to you, you know?” And I began to kind of, you know, it's unfortunate and it felt very discouraging. It really felt belittling even—to realize that, “You know what? I don't really have a fair chance at, you know, going to seek medical care.” Um—just at face value,<sup>18</sup> because visually when you see me come I already now have at least two potential barriers to our communication, as well as you know how you treat me: my actual medical treatment. Bedside manner aside, that—you know that that's a whole other monster in and of itself, but which a lot of people do experience, but I just kind of began to realize like, “You know, you're going to have to approach this differently.”

**AD: Mm-hmm. Mm-hmm.**

TA: You know.

**AD: I was just gonna ask how would you describe your health up until your experience with COVID. Would you describe yourself—?**

TA: Yeah. Um—I was—I wasn't very active, but I wasn't sedentary either. Um, I had good health, I think, um, the only thing; I would kind of have these joint problems, you know? Like, you know, inflammation,<sup>19</sup> you know, in my joints—a little bit of arthritis,<sup>20</sup> that type of thing.

**AD: I see.**

TA: Back pain: very mild though. Wasn't, you know, anything that was like “Oh, you have chronic pain.”<sup>21</sup> You know, I would have these, you know, just kind of here-and-there conditions where it was usually my joints or something, you know, were hurting. But yeah, and that was pretty much it, you know?

**AD: Between the time you started seeing your PA for the headaches: How long did it take for you—or did you begin to feel better—or has that been sustained up until this point?**

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<sup>18</sup> Face value figuratively refers to the superficiality of something. “At face value definition & meaning.” Merriam-Webster. <https://www.merriam-webster.com/dictionary/atfacevalue> (accessed October 6, 2022).

<sup>19</sup> Inflammation is a complicated process when body tissues react to unwanted stimuli that involves symptoms of heat, pain, etc. “Inflammation.” Wikipedia. <https://en.wikipedia.org/wiki/Inflammation> (accessed October 6, 2022).

<sup>20</sup> Arthritis generally refers to multiple joint conditions, often involving stiffening joints. “Arthritis.” Wikipedia. <https://en.wikipedia.org/wiki/Arthritis> (accessed October 6, 2022).

<sup>21</sup> Chronic pain refers to pain-related conditions that persist over a long time. “Chronic Pain.” Johns Hopkins Medicine. <https://www.hopkinsmedicine.org/health/conditions-and-diseases/chronic-pain> (accessed October 6, 2022).

TA: No, I didn't begin to feel better, but I did at least feel seen, and I felt—I felt heard, and I mean, I wouldn't have said I felt important, but I definitely stopped feeling like a nobody. So, I'm sure, you know, this is called—we're dealing with COVID here and we're dealing with Long COVID, particularly at this time, at this point—as Long COVID. So, the doctors didn't know much at all, right?

**AD: Right.**

TA: So, there wasn't, you know—immediate or defined treatment at the time.

**AD: Sure.**

TA: But what she did do was say, you know, “Well, let me look at what I can do for you,” you know? And, “what do you—?” and she asked me, you know? She prioritized, uh, she allowed me to prioritize, you know—what was most important to me, not just for that visit, but even in my treatment, right? Versus, you know, them deciding, “Well, this is an issue medically that is more important than this issue,” you know? And COVID at the time, Long COVID particularly—it did affect you, um, psychologically. That was a huge part of my struggle: Dealing with anxiety, you know—depression. And honestly, you know—it's kind of weird. You can be afraid to die from COVID, you know—that many nights I was sleepless, insomnia.<sup>22</sup> Um—I couldn't sleep; I was afraid to sleep because I thought I might die in my sleep. And at the same time, you know—fighting thoughts of suicide, and saying, “let me just—this is just too much it's overwhelming. When is this going to end? Nobody knows anything.” You know—and, “I just want to take myself out,” you know? And, you know—I had tools to do that, and I had to talk to my family and tell them, “look guys, I need you all to take this stuff, and you know put aside, lock it up.” You know—that's how bad it was, you know?

**AD: Yeah—gosh.**

TA: Um, but you can be in this strange kind of limbo<sup>23</sup> where you're, you know: “I want to live.” And at the same time, you're giving up hope, you know? And I feel like what the PA did for me was that validation first of all: “I'm not crazy,” you know? [laughs] And even

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<sup>22</sup> Insomnia refers to conditions which make it difficult to fall and stay asleep. “Insomnia.” Mayo Clinic. <https://www.mayoclinic.org/diseases-conditions/insomnia/symptoms-causes/syc-20355167> (accessed August 20, 2022).

<sup>23</sup> Limbo here refers to when someone or something is trapped between two states of being. “Limbo definition & meaning.” Merriam-Webster. <https://www.merriam-webster.com/dictionary/limbo> (accessed October 7, 2022).

acknowledging that, you know, these feelings that I was having—they exist, and they are of the psychological nature—but yes, they are very likely linked to a physical, um, you know, beginning, right? This virus. Um—and I didn't know anything back then about, you know, brain inflammation<sup>24</sup>—uh—inflammation—you know? Those were things that weren't really explored; You really had to do a lot of homework, just to go to the doctor [laughs].

**AD: Right [chuckles].**

TA: On a regular day, and even more so during, you know, the COVID pandemic 2020—you have to do even more homework, you know, just to get referrals; just to get, you know, testing done. But again, just kind of being able to have that voice of being allowed to prioritize what I felt was affecting my life most at the time.

**AD: Mm-hmm.**

TA: And then having that consistent follow up, you know? That—that was life saving for me. Because I felt like, “it's not hopeless,” right? Even though, you know, he or she doesn't have the answer; they're at least trying. And they're really concerned about me, and they're not allowing, you know, the overwhelm of the situation to treat me as less than, you know? And that mattered a lot. Um—treatments, you know, kind of—well before we talk about treatment; lets you know—you have to look at diagnosis, right? And so, in June of 2020. I started Black COVID Survivors Support Group, okay?

**AD: Okay.**

TA: Uh—and that was because of these experiences I was having when I'd gone to the emergency room. And I was, you know, between there as well as these different satellite sites where testing you're—or you think you're going to be tested and you're not tested because you're not—you know, a frontline worker. Um—and that frustration, you know the disbelief. Like, “how can you have a headache every day. Is that really possible? You know? Like, “Yeah—It's possible. Every. Single. Day. For over 10 months in my case. But I started the group because, uh, there's that medical side of it and needing to connect with other people who understood what I was going through.

**AD: Mm-hmm.**

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<sup>24</sup> Brain inflammation here refers to encephalitis, a cognitive inflammation typically due to infection. “Encephalitis.” Mayo Clinic. <https://www.mayoclinic.org/diseases-conditions/encephalitis/symptoms-causes/syc-20356136> (accessed October 6, 2022).

TA: And I was online. There were some other groups that did that. But at the same time—we're talking about the summer of 2020. So, we're looking at, you know—political climate. We're looking at the George Floyd situation and really feeling, um, you know, just at odds with your whole country, you know? And really experiencing a very collective, you know, PTSD,<sup>25</sup> really. Um—not Floyd alone, but that was you know—kind of, you know, that true burning point that—that occurred across the nation at once, and safe space was—was needed. And—you know—being able to—to share your story with others without other people interjecting, you know—with their story, or to take away the attention, right? Or to—you know—invalidate you. Or to sit there and say, “Well, we all are experiencing the same thing,” [chuckles] you know? That—that was important: to create that space, so that we could have these conversations. We could have these conversations with a shared backdrop also, right? Of experiencing COVID and, at the same time, dealing with these social issues that are going on, and how even that played into how we were seeking treatment, whether or not we sought treatment, and then what type of, you know, treatment we received. And we heard over and over again in that time of the pandemic about people going to the emergency room, being turned away; and then going home and dying. And many of those cases, you know, they were African American women that this happened to. Um, we all know somebody, you know? There's a statistic that says 71% of African Americans know someone who died of COVID or was hospitalized from having COVID, and definitely I saw that, you know, as—as a reality.

**AD: Mm-hmm.**

TA: Um—So, just having that space, you know? Going back to why the group was created.

**AD: Yeah, that's really powerful.**

TA: Yeah. It was very important to be able to have that backdrop, to not be judged, you know? For speaking in a certain way, right? There's—there's going to be certain, you know—colloquialisms<sup>26</sup> and cultural-isms.

**AD: Right.**

TA: You know—that we're going to use to talk to one another. And it doesn't mean that I'm this or that, right? Doesn't mean, I have a—an ISM. You know [chuckles]: a sexism or racism

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<sup>25</sup> Post-traumatic stress disorder (PTSD) is a mental disorder resulted from experiencing or being exposed to an intense or damaging event. “Post-Traumatic Stress Disorder.” National Institute of Mental Health. <https://www.nimh.nih.gov/health/topics/post-traumatic-stress-disorder-ptsd> (accessed October 7, 2022).

<sup>26</sup> Colloquialism refers to the informal use of language when conversing. “Colloquialism.” Wikipedia. <https://en.wikipedia.org/wiki/Colloquialism> (accessed October 11, 2022).

or or, you know, or bigotry<sup>27</sup> or any of those things, but the context of where we were in life had everything to do with being African American.

**AD: Mm-hmm.**

TA: You know—the stories that we heard on the news. You know, as far as those who were turned away.

**AD: Right.**

TA: As far as how heavily impacted we were. When you looked at even, you know—where are those hot spots for COVID? I remember them doing a list of zip codes,<sup>28</sup> and my old neighborhood in Chicago, you know—I grew up in community called Englewood. And the zip codes, you know, were there, you know, for being heavily impacted, you know? [brief pause] It was necessary. And—and I think in doing so a lot of lives were saved. I know mine was. You know, it's funny that you can be reaching out to help other people, and at the same time drowning.

**AD: Mm-hmm.**

TA: And we hear about, “put your own face mask on first.” But I’mma tell you; I mean that was so real for me. I was struggling with thoughts of suicide. And at the same time [chuckles], you know, reaching out to others saying, “Hey guys! Let’s band together, you know? And get through this thing!” You know? Um—

**AD: Wow.**

TA: Yeah. Um—

**AD: What was the response, did you-- was it pretty immediately met with interest, did you—?**

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<sup>27</sup> Bigotry refers to systematic prejudices against certain groups of people. “Bigotry Definition & Meaning.” Merriam-Webster. <https://www.merriam-webster.com/dictionary/bigotry> (accessed October 11, 2022).

<sup>28</sup> The US refers to postal codes as ZIP codes. “ZIP Code.” Wikipedia. [https://en.wikipedia.org/wiki/ZIP\\_Code](https://en.wikipedia.org/wiki/ZIP_Code) (accessed October 11, 2022).

TA: It—it was actually. Um, so, and—and I found interesting. So, in order to find my group on Facebook<sup>29</sup>; you would have to put in Black COVID. You know, you have to put in the word “Black” or “African American,” right?

**AD: Right.**

TA: But when it came a COVID in general, if you looked for support groups you would get these, you know, really big diverse groups like, “Survivor Corps,”<sup>30</sup> and there are a couple others that were well known. So in order to find my group; you had to be very specific about what you typed in search.

**AD: I see.**

TA: And so, yeah. When you think about what it took to kind of find me? Yes. It was a very good response. It probably took maybe just a few weeks before people began to really pour in. And you know—um really just, you know, someone told another person [who] told another person. I had—had a classmate. And this was another reason. When I began the group, it wasn't just for those of us who were sick with COVID or Long COVID, but those of us with just lost family members, were dealing with family members who were sick. That's a—that takes a lot too, right? To be a caregiver. And people not even realizing you're in a caregiving situation.

**AD: Yes, right.**

TA: You know? But I had a classmate who had lost like five family members in a very short period of time. It had probably only been about six weeks or so. And I—and we began to kind of talk back and forth in the DMs (direct messages), and—I just felt for him so badly like: goodness! You know, all around you, you just literally seeing your family disappear. You know, the elders of your family, and you know, just, you know, it was—it—I saw that those people needed support as well. So it wasn't just to get through the sickness, but we don't oftentimes think about the fallout, right? We just kind of think about, “who's been affected, right now? What does that look like?” And not that domino and emotional effect;<sup>31</sup> the financial strain; the—you know, the added responsibilities, you know? That come along with other people around you suffering. And I read recently that there's over 200,000

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<sup>29</sup> Facebook is a virtual service for media and network offered by Meta Platforms. “Facebook.” Wikipedia. <https://en.wikipedia.org/wiki/Facebook> (accessed October 11, 2022).

<sup>30</sup> Survivor Corps refers to a global connection of survivors offering each other collective support to heal from wars. “Survivor Corps.” Wikipedia. [https://en.wikipedia.org/wiki/Survivor\\_Corps](https://en.wikipedia.org/wiki/Survivor_Corps) (accessed November 1, 2022).

<sup>31</sup> Domino Effect refers to the phenomena when one event initiates a mass of similar occurrences. “Domino effect.” Wikipedia. [https://en.wikipedia.org/wiki/Domino\\_effect](https://en.wikipedia.org/wiki/Domino_effect) (accessed October 11, 2022).

children who lost a parent to COVID. And—and thinking about that—a lot of those children are Black and Hispanic children. Um—and so, when you, you know, what happens to them, right? So they're either going to end up in, you know, foster care system, even if temporarily, or they're going to now become the responsibility of family members who themselves are already, you know in a marginalized, you know, society, right? Who already have limited resources for themselves, let alone—the unexpected additions, you know, that come to their household. And so, there was, you know, I just found it necessary to open that up to them as well, and allow them to talk about, you know, what was going on. I've had, you know—in the group we've had spouses, you know, they weren't sick, but they were—joined the group because they just needed to see what was going on, you know? They needed to see someone else say what their loved one was saying, and it helped them to even be a better support to believe, you know—their family members the first time they told'em, you know?

**AD: Mm-hmm.**

TA: And for us to really share, um—what were some of the, you know—progresses that we were making, right? So, if I'm going to the doctor, and you and I can both go to our physicians, you know, about the same problem, same, similar history. But one doctor may say, you know, "This would be your treatment." He might give you something very mild. And another might say, "We have testing available for, you know, this, that, or the other, right?" And so, being able to even share, "Hey, when you go in—ask them to test you on this, you know—for this. Ask them to give you this type of scan. This is what my doctor did, for me, you know?" And sometimes those tests came out, you know, with conclusive evidence, and oftentimes, dealing with Long COVID, things came back normal. But it was still good to know that, and it's also a certain type of reassurance and confidence that you have when your physicians take the time to deal, you know, delve deeper into what's happening to you, right? You know—with these additional tests, with these additional labs and things like that. But again, that goes back: we still had to do that homework. You know, you had to come into the group, you had to look; you had to ask, you know? But you did also see, you know—automatically—other people's journeys and use that to help yourself.

**AD: Uh huh. Right. And so, you had mentioned a bit ago about treatment. Is that something that sort of emerged through conversations that were happening in your group?**

TA: Absolutely, yeah. Mm-hmm. Yeah. Hearing about, um, you know, certain tests that were being done. Like, I didn't know, for example, with the headaches, right? Be having—and I forget the name of it now—but I had the brain scan where they put you in the machine and they roll you through—to not just look at, you know, my brain. But to, you know—look at

other parts of the—my um—neurological system to find, you know—what could be the source, right? Of these headaches. And we can't just keep saying that it's stress without ruling out these other conditions, right? Um—and so, many people—you know, “Thanks for letting me know about such and such. I went to my doctor about it.” Or, “Thank”—you know—there was—that peer help. That's what peer help is, right? Is—is sharing your experiences. Your stories are so important. You know—they're not just there for sensationalism.<sup>32</sup> You know, or to—to keep, you know, um, highlighting the problem, but they're there so that we can also talk about how we made it through. You know, in the Black community, especially the—the church community your testimony, you know, is often a big part of that culture. You know, and hearing from other people how you made it over; how you made it through you know—through your—through your difficulties, over the mountain [chuckles]. You know, all these [laughs] different euphemisms<sup>33</sup> we use. But yeah, um, sharing led to us being able to equip ourselves.

**AD: Mm-hmm.**

TA: And it kind of, you know, empowered you: “Okay. I know what to ask, you know—when I see my physician.” And myself, you know, I've always been a very curious person. Um—at one point I taught science; I taught biology. So, I would say that I had a certain confidence even—and um—when talking to my physicians. But not everybody has that background, right? And all the times there is a power imbalance between patient and physician—on any given day. And then that's amplified when you have a difference in education, when there's a difference in, you know, perceived, you know, class and so forth. And so, being able to give people very practical steps, “Hey, do this. Ask about that; you know? If this happens: here's your recourse.” And—and that's where I really began to see the importance of this group, um, is to educate the audience, to advocate for them, but also to give them tools and strategies for self-advocacy, right? And then to get their participation—more often. To stop seeing ourselves as being on that fringe—to see that, you know what? We can be a part, you know—of—of the main movement: be it medical, you know, be it gender-related issues, that you can assert yourself, and you don't have to wait for an invitation.

**AD: Mm-hmm.**

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<sup>32</sup> Sensationalism is a term in journalism referring to the biased or overloaded usage of emotion on reporting news. “Sensationalism.” Wikipedia. <https://en.wikipedia.org/wiki/Sensationalism> (accessed October 11, 2022).

<sup>33</sup> Euphemisms refers to language that softens or avoids originally offensive or pragmatic terms. “Euphemism.” Wikipedia. <https://en.wikipedia.org/wiki/Euphemism> (accessed October 11, 2022).

TA: You know, you—you can go there and say, “I deserve the same things as anybody else, and that should not be predicated based on whether or not, you know—I tugged at you to get that service, right?”

**AD: Right.**

TA: So, you know that part of the group, you know—the self-advocacy, is one of my main missions, is to equip all of our members, our participants, you know, with specific things that they can do when you're not feeling like that you're getting the best care. Or, you know, what do you do when you've been treated with that bad bedside manner?<sup>34</sup> You know, maybe not by the doctor—could have been the check-in person. You know, but what do you do, what is your recourse? You just take it? And, “I know I’m going to have to deal with this lady at the check-in desk, but once I make it back to my doctor, everything will be okay.” But there's still: you don't have to accept that, you know? Um, and then oftentimes we just don't know—that there's something that can be done about it. We often think that things have to be, you know—at this catastrophic, you know, newsworthy level of seriousness, to think that is something that we can stand up for ourselves about.

**AD: Right, right. So, how would you say the organization has changed. If it was founded in June 2020 and we're now in July 2022, what's been the arc of—?**

TA: Yeah, we're definitely much more purpose-driven. And again, it started off as a support group, you know—for myself [laughs]. And, you know—I accidentally got involved in activism, you know—but since then, Black COVID Survivors um—has been rep—has uh—been present as a representative of the Black COVID community um—in speaking with the White House Task Force;<sup>35</sup> in talking with the NIH (National Institutes of Health)<sup>36</sup> uh, and helping to, you know, define uh—what would be good community engagement strategies. And uh—we've been in these conversations, you know, that kind of bring attention, not just to—to the fact that Black people are suffering, but that we actually, we do have answers; we do have ideas that can contribute to the work. And so we've been able to, you know, have a voice and a platform as Black COVID survivors to speak with these other institutions and be heard and be seen.

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<sup>34</sup> Bedside manners refer to doctors' interactions and attitudes towards patients. “Bedside manner.” Merriam-Webster. <https://www.merriam-webster.com/dictionary/bedsidemanner> (accessed October 13, 2022).

<sup>35</sup> During COVID pandemic, White House under Trump's administration established this task force to respond to this disease. “White House Coronavirus Task Force.” Wikipedia. [https://en.wikipedia.org/wiki/White\\_House\\_Coronavirus\\_Task\\_Force](https://en.wikipedia.org/wiki/White_House_Coronavirus_Task_Force) (accessed October 13, 2022).

<sup>36</sup> NIH, or National Institutes of Health, is a U.S. federal unit that supports biomedical research and its application through research and funding. “National Institutes of Health.” USA.gov. <https://www.usa.gov/federal-agencies/national-institutes-of-health> (accessed October 13, 2022).

**AD: Do you have other folks in leadership now, or are you still—?**

TA: I do, and—and that's one—one aspect, another thing that has changed. And that is also still in progress, with trying to raise up other leaders within the group. Um—there are others um—uh, who are involved, you know—and be—because we are officially a nonprofit; we do have a board of directors. But there are also others who are who are involved in, you know—the advocacy work, and we're about to get out into the community physically—uh boots on the ground—in collaboration with other organizations to uh, bring that education specifically to Black communities. And to, you know—show them the way in a way [chuckles], you know? A way, not the way. But show them a way, right?

**AD: Right.**

TA: To make it through this uh—pandemic and to as well, have tools that can be used going into the future for getting the health-justice that they deserve.

**AD: Mm-hmm. What's that going to look like with you—you said that boots on the ground is about to happen. What will that look like?**

TA: Yeah, so, um, you know, I find it important—again my background been in education—you can't make good decisions if you just don't know, right? And so, you know, that old adage is that, “knowledge is power.” Bringing community health education to certain areas is a big priority, and particularly with um—research literacy. So, you know a lot of people do focus on um—health education, which I do feel is important as well. Um—especially when it comes to preventative, you know—conditions and—and care chronic illnesses and stuff that is overwhelmingly again affecting the Black Community when it comes to diabetes and high blood pressure, heart disease, those types of things. But one of the reasons why we don't have as much justice as we should, is that we're not represented on all levels of—of the medical system.

**AD: Mm-hmm.**

TA: And so, in order to get you to participate in health research and medical trials, we have to back up a bit and talk about why you're not.

**AD: Mm-hmm.**

TA: And the reason why you're not is because you either have misinformation, or you're making your decisions still based on old information and old atrocities, you know, that have happened. Some of them still even being recent, you know? A lot of people refer to the

Tuskegee experiments;<sup>37</sup> we've all heard about it; you know, you didn't have to live through it, because your grandparents told you about it, your aunties told you about what they did. You know—to those people, and um—but there's beyond that. There are other instances like, you know—like during the—the you know—the drug, the crack epidemic of the 80s,<sup>38</sup> where um, mistrust developed from Black mothers being tested for drugs at delivery.

**AD: Mm.**

TA: Whereas that was not uniformly being done to all mothers in delivery, but it was something that was targeted at Black inner-city mothers. And so, they would have these babies, find out, you know—that they were drug positive, and then now we have, you know—child protective services coming in to take the children that are already at home, as well as, you know, the children that they had just given birth to. Um, so there—there's been a history, an ongoing, you know, type of history that goes beyond Tuskegee. That has been internal, and that we all talk about but maybe, you know—the news may not speak about it, but we all mumble amongst ourselves, right? About the various things that have occurred medically. Um, so going back to the need to say, “Okay, you may be making decisions about your participation, based on old information, under old systems now. You need to know what this research like now; there's lots of oversight. There's a whole lot of patient rights um, that are now talk to you before you participate.” But people don't know that because they won't even step close enough to, you know, to a research project or a study. You know, to get that information. Even when it comes to—and speaking of “study,” one thing also that it's kind of a misunderstanding in the Black community is that research means experimentation. And they tend to think of them as being one and the same. And so, we talk about education about kind of this baseline of research literacy, that all research is not about experimentation and what you're calling “experimentation” you might actually mean medical trials and interventions.

**AD: Mm-hmm.**

TA: But don't let that stop you, again from other aspects, you know—of people understanding your historical experience medically. Understanding what you're currently living through, you know, so all of that is necessary in order to let people understand that,

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<sup>37</sup> The Tuskegee Experiment was a damaging study on syphilis carried out directly on African Americans in Alabama. It consequently caused several deaths. “Tuskegee Syphilis Study.” Wikipedia. [https://en.wikipedia.org/wiki/Tuskegee\\_Syphilis\\_Study](https://en.wikipedia.org/wiki/Tuskegee_Syphilis_Study) (accessed October 13, 2022).

<sup>38</sup> Crack epidemic refers to an outpouring in crack and cocaine usage during 1980s-1990s period that resulted in overloaded social crimes and violence. “Crack epidemic in the United States.” Wikipedia. [https://en.wikipedia.org/wiki/Crack\\_epidemic\\_in\\_the\\_United\\_States](https://en.wikipedia.org/wiki/Crack_epidemic_in_the_United_States) (accessed October 13, 2022).

“Okay, I do have a certain amount of power. This is not a situation in which I’d be walking in blindly and helpless to whatever, you know, the mad scientist want to do. But this is actually: I can contribute in a safe way, and I have the right to stop at any moment. I have the right to ask questions, and I have a right to ask that same question again if I still need clarity.” You know, and so that’s what where we’re headed, this is what—what is important to me as a, you know, as a health advocate and activist, is to empower others to kind of help. First of all, let’s strip away all that baggage, right? We have baggage, and we have so many things that limit us. That we don’t step forward to either A) speak up about things that have gone wrong; we don’t speak up to demand, you know, that things should be better. And we also oftentimes don’t see ourselves as—as just part of the regular narrative and development and advancement of science—overall. So, where we’re going is, you know—the boots on the ground: let you see me; I see you, you know? And bringing, you know, that education to people through community outreach, and also online. Setting up, you know, learning portals and incentives for people to learn about um—research literacy. And then, also, you know—what are your alternatives when you do encounter problems? Nobody—I mean, most people don’t know, you know? [chuckles] It’s a very extreme circumstance, with a doctor saying something very, very rude to me, and I was just like very devastated about it. And I told my mom about it, and I think she has spoken to someone at her job about it, who was a nurse who—who then explained, you know, what I could do next, and speaking with—you know, your clinics have these managers, right? And they have these directors, but we don’t all oftentimes know what that structure leadership is. You go to the doctor and that’s kind of like the end of it, right? It’s a—it’s a building and doctors are there. We don’t oftentimes think about the fact that there is somebody over them, and that they have to be accountable to another board, right? Or director and so forth. So, that’s all part of that health literacy<sup>39</sup> and just, the more we know, the better we can make good decisions, and we can make decisions that aren’t based on fear, and decisions that aren’t based on, you know, myth and misinformation.

**AD: Mm-hmm. Yeah, that’s really powerful. So, you described earlier headaches that lasted for 10 months. How would you describe your health status now?**

TA: You know, I feel like I’m in good health. Physically, I think that I have recovered I would say, a good probably 90%. I still have—

**AD: —I’m sorry, is there anything that you attribute to that or is it just sort of the tincture of time?**

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<sup>39</sup> Health literacy refers to the capacity of organization and individual to spread and obtain medical knowledge respectively for well-informed health decisions. “What is Health Literacy?” Centers for Disease Control and Prevention. <https://www.cdc.gov/healthliteracy/learn/index.html> (accessed October 14, 2022).

TA: I think is a combination of time, and being able to have the time off to heal. I lost my job—not by choice. But you know it—it was just something that happened. Um, I wasn't able to do what I had done, you know? I became—I was just wasn't able to fulfill my duties, and a lot of that had to do with those cognitive deficits that were happening. But in fact it turned out to be a blessing, you know, so being let go from that allowed me to just really have a chance to breathe, you know, to recover emotionally—from all that was happening. To get the treatments, you know? Another issue, you know, when you're working, um, being able to take time off to go see, you know—a therapist or talk with a counselor, you know? That time [brief pause]—they were swamped [chuckles], and still are, you know? [chuckles] So, it was very difficult to get an appointment, let alone, you know—once you get one, to be able to, you know—have consistent appointments and that—things—of that nature.

**AD: Right, right. Yeah. The luxury of time.**

TA: Mm-hmm. So, you know—and that's just, you know—being a second income earner, you know, in the household. Very, very important, but at the same time, you know, you learn to scale back on what you can, and you—you do what you've always done, which is, you know, you just make the right things happen, you know? And you still support your family. And—and we're not falling apart and I could be grateful for that. You know—my husband is well employed, but—just having that time off again gave me the ability to focus on myself, and to begin to look around and see that, you know what? Not only, you know, can you continue to help other people. But you can also accept help from others too. And accepting help from others wasn't something that I don't—ever been pretty good at overall [chuckles]. You know, I've had this kind of independence, and you know—it's just like, “let me just do what I do, you know—do it by myself.” You know, and I don't want to involve—you know—have to figure out other people and so forth. But even throughout this whole process I've learned to, you know, reach across the aisle,<sup>40</sup> and accept help from others and realized, you know what? There are really good allies out there, and your allies may not belong to the same—all the same groups, as you, right? But just as we're not one dimensional; neither are they. And so, there's a lot of intersectionality, you know—that we can—we can look at, to use as our bonding point. And really bring our resources together to help one another.

**AD: Mm-hmm. Mm-hmm. So, it sounds like you do that personally. Is Black COVID Survivors Alliance also in collaboration with other groups? Is it a collaborative effort?**

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<sup>40</sup> Reaching across the aisle refers to the act of advocating or getting support from the opposing political side. “Reach Across the Aisle: U.S.” The Modern Republic. <https://www.modernrepublic.org/reach-across-the-aisle> (accessed October 14, 2022).

TA: Yes, um, and again we're working on expanding that even more as well. Um, Black COVID Survivors is working with the recover program um, that—that is um, being sponsored by NYU Langone<sup>41</sup> and the NIH. We're also a part of a Body Politic,<sup>42</sup> which was a group started by Fiona Lowenstein.<sup>43</sup>

**AD: Right.**

TA: And um, it was—she actually, I can't even remember how it all began [laughs]. But she was one of the first initial people that helped me to see, you know, that there is a work of activism here that can be done. Um, and that, even though this is Black COVID survivors, we don't have to try to do everything on our own, you know? We can still create the safe space and at the same time, you can still work with others, and learn from others, right? And also respect their experiences, even though they may not be packaged the same way that our experiences have been. So yeah, it was, um, I would say that would probably be the main group, um, and—and if you're—may or may not be familiar with Body Politic, it is a feminism activist group that fights for health justice.

**AD: Right.**

TA: Um, and one of my early collaborators was actually Hannah Davis;<sup>44</sup> she was from there as well, and she was one of the few people who had reached out to Black COVID Survivors that I felt really had our best interest in mind. So, um, once we were formed as a group, you know, our numbers are growing, and I'm, you know, being inundated by requests from various universities, various researchers, various doctoral students, who all want to come into the group, and, you know, give their survey and invite our members to their, you know, research site and etc. And I began to, you know, feel like, "Jeez everybody's just kind of knocking at the door, but I don't really hear too many people, you know, saying what the exchange is." It's just kind of, "Hey, let me throw around the word, 'health equity,' you know, and get you signed up on what we're doing."

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<sup>41</sup> NYU Langone Health is a top-tier medical research center in the U.S state of New York. "Our story." Patient Care at NYU Langone Health. <https://nyulangone.org/our-story> (accessed October 14, 2022).

<sup>42</sup> Body Politic is a cooperative wellbeing space driven for and by queer feminists. "Body Politic." Body Politic. <https://www.wearebodypolitic.com/> (accessed October 14, 2022).

<sup>43</sup> Fiona Lowenstein is an independent writer, speaker, and producer, focusing on gender and sexuality, health justice, etc, and another GFP interviewee. "Fiona Lowenstein." Center for Health Journalism. <https://centerforhealthjournalism.org/users/fionalowenstein> (accessed September 28, 2022).

<sup>44</sup> Hannah E. Davis is a Long COVID-focused researcher and founder of the Patient-Led Research Collaborative, in addition to being another GFP interviewee. "The Pandemic After the Pandemic." The Atlantic. <https://www.theatlantic.com/health/archive/2022/03/long-covid-risk/627031/> (accessed October 14, 2022).

**AD: Uh huh.**

TA: And—once I began to really see that as a one-way transaction, I kind of got a little bit closed off. In the beginning, I allowed anyone into the group. And I did, you know, had to have the condition that you didn't have to be Black to come into the group, but you did have to be Black in order to speak. So, if you're here, you know, come in, be quiet, listen, learn. But don't interject yourself into, you know, our stories, into our experiences. But Hannah was one of the people who ended up in—in the group. Um, and she came; I think what was she showed me was that, you know, again, there are true allies who aren't just, you know—using Black people as a—as a front—to their work. But who actually und—believe, you know—in the need for us to be elevated.

**AD: Mm-hmm. Mm-hmm.**

TA: And, and for our conditions to be amplified while at the same time saying, “I know you're experiencing a unique experience, but at the same time we also are experiencing parts of this, and we can all work together.” And so, you know, the fact that she uh—not only were, did she get participants from our group as part of the study that they were doing at the time with PLRC (Patient-Led Research Collaborative),<sup>45</sup> but she brought it back around which no one else had done. No one else that come back to say, “Hey, here are the results of that study that we were doing: the survey that I asked, you know, you and your members, you know—to do.” And that was very important. Um, and I think that was really a game changer too as far as showing me that, “Okay, you know we don't have to be so guarded,” you know? And it also showed me how to prioritize who I work with as well. You know, and that's another, you know, big part of navigation, you know, as a—as an accidental activist [laughs] is, you know, you have—there are many opportunities, I think, to collaborate. But all exchanges are not equal exchanges, right? And so, that's—that's the biggest point. It's not important to me to have, you know—to just say, “Oh look at these two dozen people that I'm working with.” I'd rather have, you know, a handful of partnerships and collaborations that are very meaningful and give back to the-- to my members directly than, you know—to look like I'm collaborating with, you know—dozens of other groups.

**AD: Right, right. that makes a lot of sense. So, you've described yourself as an accidental activist and a health advocate and you talked earlier about how gender became more salient in the clinical experience for you as you went through your experience with COVID. I'm curious how you now understand stand the term,**

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<sup>45</sup> Patient-Led Research Collaborative (PLRC) is a collective of researchers who have experienced Long COVID. “About the Patient-Led Research Collaborative.” Patient-Led Research Collaborative. <https://patientresearchcovid19.com/> (accessed October 14, 2022).

**“feminism”? You know, what that means to the work that you do, and if you consider yourself a feminist?**

TA: Great question [laughs]. Um, for me—um—I would say that the way I would define feminism is—is not so much—[pauses]. It's not so much like moving toward equal rights, but it's not being inhibited by my sex.

**AD: Mm. Mm-hmm. Mm-hmm.**

TA: I think there's, you know, kind of a real big divide in the feminism movement. You know—there's the fight against the male, you know, patriarchy, right? The white cis-male and, you know, wanting to kind of level up to where they are—is one view, you know, of feminism. And then there's the um, I'm sorry [chuckles].

**AD: No, you're fine [smiles].**

TA: There's—there's this other aspect of feminism, like increasing your importance and your visibility.

**AD: Mm-hmm. Mm-hmm.**

TA: Okay? And so, the way I see feminism is not so much a fight against—

**AD: Mm-hmm. Mm-hmm.**

TA: But more of a, um, utilizing the current power, and your unique abilities that you as a female or, you know, be it gender or just by sex, can bring into society. You know, so it's not just, you know—“let me get to here.” But realizing that power is already here, and we just need to leverage that power in order to assure that we're receiving the same, you know—access. You know, to—to resources to, you know, just you know every institutional, you know, aspect out there.

**AD: Right, right. And so, do you in terms of the part of considering yourself a feminist, is that frame your vision for yourself?**

TA: I wouldn't say—well [brief pause]—that's a good question. I feel like you have to be a feminist, when you're talking about health. You cannot separate the fact that you are female or that you identify as a woman from the work of getting health justice. They're there—they—they go together, you know, historically, you know—whether it's, you know, being in on the side of discovery or being on the side of, you know, being the patient—or victim,

unfortunately. There's—there's been a lot of sordid history there with—with women. So yeah, in this work—you have to be a feminist. And that's, you know, when I think about who I have to equip, you know—with strategies for getting good health care—is usually the women. You know, in a group that I have to advise, and that we're giving these strategies to, or who find more often than not, that they are going in circles, you know, about the same issues with their physicians. Not that men don't experience it, but overwhelmingly, you know, we—we see this imbalance in treatment and bedside manner when it comes to female patients. But yes, in that aspect, for sure; you can't not be a feminist if you're fighting for health justice.

**AD: Mm-hmm. And you did that early on, in sort of expanding what's included in justice, not only with COVID but health justice as linked to racial justice, and that seems to be to have been a part of this from the beginning for you and part of the vision for Black COVID Survivors Alliance. So, I think that's such an important contribution, you know, to the work that's being done and to this archive. Looking forward, what do you think—what does the future look like for you and then for the group? What are some hopes that you have?**

TA: Well, I hope um—that we can have more leaders, who are able to, you know, kind of create these—these satellites, or these other, you know, localized um—aspects of what we do. So that, you know, we're not just seen as a headquarter here in Atlanta, but that we have chapters, you know, throughout the United States. That's where our members come from; they are already throughout the United States and there are a few that are international. But to really just see other leaders rise up, and who will continue the work that is patient centered, patient first—is not about politics, is not about legislation for us—is not about, you know—all of—all of these constituents, but it's really about service first. And service first to, you know, to the patients. And that's what's most important and that's where I see the group going—is just really being, you know—forward facing. You know, programs that affect people, and people can say, you know, directly, “I know for sure that this group here came in and did X, Y, Z; you know, and helped us and we saw them. And we know that they, you know, had similar experiences.” So, you know and that's my wish and hope for—for the group is that, you know—we will have these leaders and—and other, you know—satellites that will rise up in their cities and—and really provide this um—the education and the advocacy as well as uh—getting the—the partici—participation and buy in of Black people into medical research and discovery.

**AD: Mm-hmm. So, in addition to thinking about health equity in the context of COVID, in addition to research literacy, which seems to be a huge focus for your group, are there any other thoughts and suggestions about reducing obstacles to health equity in the context of COVID?**

TA: Oh they're quite a [chuckles]—they're quite a few, yeah. Um, you know, we need our—our doctors, our facilities to be much more, you know, there needs to be more diversity training. Um, and they need to also be become more aware of what their biases are. One example: there was um—and this has happened with several people—but the first one that kind of stuck with me was a young lady in our group who uh—has been losing weight because of Long COVID and she's just you know, in her eyes—she's shrinking up, you know? She's like, “I’ve lost so much weight, I can see my bones.” But when she goes to the doctor, her white doctor, what he sees is, “Oh good, she needed to lose weight anyway,” um, you know? And that's something, you know, that when we talk about diversity training that, you know; yes, you know—overall, you know, we have a different, um, we have different—[pauses]—like, our priority of when we are at a point of health and when we're not at a point of health—isn't all built on our size, right? But oftentimes that's the first indicator. So, as a woman, when I go to the doctor and I have a problem, one of the first suggestions, is that, “Hey, if you lose some weight that'd help with your condition.” It doesn't matter what it is: my finger be falling off, and this, “You know, if you lose some weight, it'll help it heal faster.” [laughs] And, you know, African American women do seem to have a higher average weight, you know, in the United States, you know, all of us are overweight, you know, in the US as far as the average American, but just within our group, right? And so, now if I'm going to the doctor and then I'm expressing this concern to you about this dramatic amount of weight I'm losing. And you're simply seeing it as, “Well, you're just getting down to the baseline you should have been at in the first place, you know?” And I see it, and know it to be a physical problem, right? I'm—I'm not getting the help that I need from you, right? And so, it's that type of diversity—diversity training and awareness that more doctors need—uh, need to have, and so the advisement part of what we do is important. You know, um, and highlighting what we're experiencing, you know, and things to just be really aware of, because there's a lot of bias, you know, there's a lot of bias that—that doctors have that comes from the training, and then just their individual biases.

**AD: Mm-hmm.**

TA: You know, will affect how they perceive the importance and the prioritization of our complaints. So, no, it may not, you know—on your scale; I might have gotten within the range of what might be let's say a “proper BMI,”<sup>46</sup> right? But, for me, if—if this is a weight loss—dramatic weight loss drop in a short period of time, and this is not what I want for

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<sup>46</sup> Body Mass Index (BMI) is an index indicating one's body fat concerning their weight and height. “Adult BMI Calculator.” Centers for Disease Control and Prevention. [https://www.cdc.gov/healthyweight/assessing/bmi/adult\\_bmi/english\\_bmi\\_calculator/bmi\\_calculator.html](https://www.cdc.gov/healthyweight/assessing/bmi/adult_bmi/english_bmi_calculator/bmi_calculator.html) (accessed October 14, 2022).

myself, right? Then that power back over my body; you don't get to decide, you know—what should—what I should be happy with, as you know, my—my ground point of good health. But unfortunately that's, you know, just one example of how a lack of cultural sensitivity and understanding uh—from physicians can lead to a lot of our concerns being dismissed—um, and not addressed.

**AD: No, it's an illuminating example. As we sort of close, is there anything that we didn't get to talk about that you wanted to mention?**

TA: Um, we're looking to collaborate and partner with others and, as I said, come to an understanding that, you know, we can still have our safe space and at the same time, really, accept the allyship that is being offered. And so, I do invite, you know, anyone else who would like to work with Black COVID Alliance Survivors as a resource, as a sponsor, as a collaborator, to reach out: the website for us is [www.bcsalliance.org](http://www.bcsalliance.org).

**AD: Great.**

TA: And you can reach out, contact me there as well as directly to my email at [teresa@bcsalliance.org](mailto:teresa@bcsalliance.org), and I'm definitely, you know—open to these conversations about what we can do to help one another, you know? And how can we all get justice because really, if we allow injustice to exist for one group it's only a matter of time before it spills over and spreads to others.

**AD: Mm-hmm.**

TA: So we can't put our head in, you know, in the sand and think that, you know, if it's not affecting me then, you know—I should—it doesn't matter. Or, even the opposite that just because it's affecting me doesn't mean that it's not affecting others, and it doesn't mean that others don't have, you know, an equal fight, you know, in their claim for what are—really should be—basic human rights.

**AD: Mm-hmm. Well, thank you so much for being here.**

TA: Thank you for having me. I'm so glad to have been able to speak about this.

**AD: We're grateful to have your story as part of this archive, and I know we'll all benefit greatly from it being part of the Global Feminisms Project so, thanks again.**

TA: Appreciate you. Thank you.

**AD: Take care.**

TA: Buh-bye [waves hand]