

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

SITE: UNITED STATES

**Transcript of Fiona Lowenstein
Interviewer: Abigail Dumes**

**Location: Virtual
Date: December 27, 2021**

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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*, *Vox*, *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 November 2022 from The Experiment.

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.

Abigail Dumes: Hi, my name is Abby Dumes. My pronouns are she/her/hers.

Fiona Lowenstein: And I'm Fiona Lowenstein, my pronouns are they/them, and I am a white person with a black t-shirt and blonde hair combed back sitting in front of a glass door that is showing a little bit of the view here in the central coast of California this morning. And I'm sitting on a white armchair.

AD: Wonderful. Fiona, thank you so much for being here and being willing to share your story with the Global Feminisms Project. We really appreciate it. And we're going to briefly introduce you and then I'll move on to the interview questions. So, Fiona Lowenstein is an independent journalist, TV producer, and speaker whose work focuses on health justice, wellness culture, gender, sexuality, and the media. Fiona graduated from Yale University¹ in 2016 and while there was a member of Yale Radio, Yale's quote, "oldest only feminist comedy troupe," and was editor-in-chief of Yale's Feminist publication, *Broad Recognition*.² In 2018, Fiona founded Body Politic, a queer wellness collective, that has transformed into a grassroots patient-led health justice organization. And in 2020, they co-founded the Body Politic COVID-19 support group,³ which now serves over 11,000 patients across the world. So, I thought we'd start a little bit with some background about your life and where your story begins. That is, how would you describe the journey that brought you to where you are today?

FL: Yeah! So, it's kind of funny because I think if you had like told high school Fiona that I... you know... they would be very involved in public health in some regard, I would have been like, "that's a curve ball..."⁴ [laughter]. Because I am a science person? And obviously some of that may have been the way that science is taught and who is kind of socialized to—you know—identify with certain STEM subjects. But, looking back on it, there were a lot of kind

¹ Yale University is a private research university in New Haven, Connecticut. It is a member of the Ivy League, as well as one of the most prestigious universities of the world, ranked 8th best by Times Higher Education as of 2022. ("Yale University." Wikipedia. Accessed June 29, 2022.

https://en.wikipedia.org/wiki/Yale_University)

² Broad Recognition is an online intersectional feminist publication maintained by Yale students with a focus on criticizing prevailing systems of power and the status quo, promoting the concept of "communities of love" instead. ("About." Broad Recognition. Accessed June 29, 2022. <http://www.broadsatyale.com/about/>)

³ Body Politic was founded as a support group with the main goal of providing a welcoming and inclusive space for people with disabilities and chronic issues to talk about issues related to COVID-19. ("About Body Politic." Body Politic. Accessed June 29, 2022. <https://www.wearebodypolitic.com/about-body-politic>)

⁴ An expression used to describe being presented with a surprising and hard problem or question ("Throw (someone) a curve/curveball." Merriam-Webster.com Dictionary, Merriam-Webster. Accessed April 8, 2022. <https://www.merriam-webster.com/dictionary/throw%20%28someone%29%20a%20curve%2Fcurveball>)

of early experiences in my life that I think led to me having somewhat of a... I guess... just a long [unclear] in our country. Sorry, can you still hear me? I know it just...

AD: It was just a little bit of a pause, so maybe...

FL: Okay, yeah. So, growing up there were a few kind of formative experiences and relationships that I think made me actually kind of... poised me to speak about public health and have an understanding of healthcare in this country. So, the first was that I was really lucky as a kid to grow up with Barbara Seamen⁵ as a mentor. She is a... she was a leader in the Feminist Health movement and was a... her like kids went to high school with my dad, was a family friend, really kind of took me under her wing. She was a huge, huge influence in my feminist journey as well because when I was like, you know... 8, 9, 10, 11 up through middle school, she was bringing me to documentaries screenings and introducing me to feminists of her generation, but also younger feminists and one of the things that she did so well was really trying to build a very wide network of people. So, she was in touch with—you know—feminists that at that point were in their 20s and 30s and connecting me with those people. And of course, she had this very radical stance on health justice, and she talked a lot about issues with the birth control pill, issues with hormone therapies, for people going through menopause... that was kind of her... what she was digging into at the point that she passed away when I was around 14 or 15. So I think that was something that really shaped my perspective on both feminism and health justice. And... I just wish I could have a conversation with her today because I feel like she's been so influential in my... in my work today. In addition to that, I grew up with parents who were self-employed. My parents were artists. They did not have employer-based health insurance. I have one parent with a pre-existing condition—with an autoimmune disease.⁶ And so I just grew up seeing kind of how a fractured healthcare system can impact—you know—a family in that situation. And also, just grew up seeing how limited my parents' ability to get the care they needed for both themselves and for me would become just simply because—you know—they were not independently wealthy. They did not have a financial safety net to fall back on necessarily, and of course, they were constantly trying to switch plans and that sort of thing. So healthcare and health insurance was just a huge topic of discussion when I was growing up ever since I was very little I remember my parents being on the phone and arguing about things and sharing some of that with me. So I think... I think both of those

⁵ Barbara Seamen was a writer and women's health activist who lived in the late 90s. She co-founded the National Women's Health Network, which sought to address birth control methods and expose potential dangers and risks. ("Barbara Seamen." Women's Health Specialists. Accessed July 5, 2022. <https://www.womenshealthspecialists.org/about/the-womens-movement/barbara-seaman/>)

⁶ Autoimmune diseases are conditions in which the body's own immune system releases autoantibody proteins that mistakenly attack healthy cells. ("Autoimmune Diseases: Types, Symptoms, Causes, and More." Healthline. Accessed July 5, 2022. <https://www.healthline.com/health/autoimmune-disorders>)

things had some level of impact on what I'm doing today just during the pandemic.⁷ But more kind of on [unclear] how I grew up in New York City.⁸ I grew up in a family with a lot of artists in it, with a lot of people who had kind of done something really different with their lives from what those around them were doing or—you know—their parents had done. And so, I think there was very much... I was raised to believe that—you know—you have—to some extent an obligation to the public collective, and to the people around you, and the world around you, and to try and make a difference and speak up if there is injustice in front of you. But also, this idea that the best thing you can do is pursue your passion and pursue what you're good at, and you shouldn't try to fit a square peg in a round hole or whatever they say. So I think that has also... you know, I've had a somewhat untraditional career, but that is a tradition in my family [laughter]. Yeah.

AD: It's a family convention to be unconventional.

FL: Mm-hmm. Exactly.

AD: That's really illuminating. I saw that when you were at Yale you majored in History. I'm curious how that choice reflects some of what you just told us about.

FL: Yeah. So, I've always been a huge history nerd. When I was a little kid, I used to just—you know—at the dinner table, kind of like, ask my parents—you know—that classic like annoying little kid thing of, "why is this this way?" and then they would say "well because this happened," and I would go, "but why did that happen?" You know, and it would just be like [moves hands in circular motion] an ongoing thing.

AD: "Why?" [laughs]

FL: Yeah. [laughs] And so, my parents joke that I was very little and I was asking for like books on World War I. I think there was actually like a famous story of my grandfather coming over to babysit for me and tucking me in and having to read this book on like chemical weapons [unclear], and being like, "are you sure you want to hear about this before bed?" [laughter]. I think I just... you know, I lived in New York City, so I was exposed to a lot of stuff, but I didn't travel very much as a kid. My parents didn't have that kind of money, or lifestyle and I was really curious about other parts of the world. And also spent a lot of time with my paternal grandfather and my maternal grandmother who both lived in New York City and were kind of like my primary caretakers outside of my parents and

⁷ The interviewee is referring to the COVID-19 pandemic.

⁸ New York City is the most populous city in the United States and one of the most populous megacities in the world. Along with its tourist appeal, New York serves as an important financial center ("New York City." Wikipedia. Accessed July 11, 2022. https://en.wikipedia.org/wiki/New_York_City)

spent a lot of... really loved spending time with older people honestly as a kid. And so I think was very eager to understand some of these stories from within my own family, kind of situated into a broader historical context. And so, I think I mentioned, that doing things the non-traditional way has been... has a long history in my family and the other day I realized that all four of my great-grandparents all married either outside of their either race, religion, or ethnicity. And so, I think like hearing... those were big stories that were told a lot as a kid, kind of these love stories of people crossing boundaries to be with each other. So there was a lot of just wanting to understand—you know—why was that? You know, during that time... that sort of thing.

AD: Very interesting... Mm-hmm. Right.

FL: But I also just like history because it's straightforward. Like, I thought I wanted to maybe major in Poli-Sci⁹, and then I'm like, "why are we making up all of these words?" [laughs] And like, you know... systems to describe the world, like, I kind of liked stories, and I like story-telling and history is just like one long amazing story. From while I was at Yale... I also got very into kind of... I studied with someone named Bill Rankin¹⁰ who is a professor there, who is an amazing scholar on the history of science, and he focuses a lot on cartography and mapping. So I... toward the end of my time at Yale got very interested in this idea of histories and also tools of science not necessarily being objective but being, in some ways great tools of colonization or patriarchy or whatever it is. And that was very mind-altering for me at the time, so that was a real focus as well. But within the history major, I studied a lot of... kind of took a lot of classes on social justice movements, and I also focused quite a bit at the beginning on the Middle East and Turkey specifically, because I had been kind of obsessed with Turkey as this... just because of—you know—the sheer number of important historical events since the beginning of time. I studied Turkish and traveled to Turkey a little bit when I was earlier in my career at Yale.

AD: Oh wow. So interesting. I guess thinking about how that connects to the work that you're doing today. I'm curious how you were drawn to that work between undergrad and now, and maybe in that brief time a lot has changed in the world... how that's changed for you personally, and how that has evolved, and how the work

⁹ "Poli-Sci" refers to the study and field of Political Science, which centers around a deep understanding of government and politics, as well as social relations that mold public life and relations of citizenship. ("What is Political Science?" University of Washington, Department of Political Science. Accessed July 11, 2022. <https://www.polisci.washington.edu/what-political-science>)

¹⁰ Bill Rankin is an Associate Professor in the Department of History at Yale University. His research focuses on exploring the relationship between science and space, including the environmental sciences, technology, architecture, and geography. ("Bill Rankin." Yale University, Department of History. Accessed July 11, 2022. <https://history.yale.edu/people/bill-rankin>)

has informed you personally and how your personal experiences has informed the work?

FL: Yeah, I mean... I graduated from college in 2016 so the world changed quite a bit that very year [laughs] and obviously—you know—not to say that... that election¹¹ changed things overnight, there was... a lot of that had been brewing a long time, but I was working... After I graduated, I worked in nonfiction publishing as an editorial assistant. My background—you know—I was trying to kind of pursue journalism, and so I was working on nonfiction titles, and I just remember after Trump¹² won the election this feeling of just not knowing what to do, because I was very used to, when I had been in college, when there was a crisis, whether it was a world crisis, or a college campus crisis... having my communities that I would tap into and kind of mobilize with whether it was... When I was a senior at Yale actually there were a number of big political things that happened on Yale's campus. There were a lot of protests for racial justice in the Fall and then in the Spring that made national news... and in the Spring there was an issue with the captain of the basketball team being, I think, suspended or expelled for sexual assault while the basketball team was entering March Madness¹³ and it became this huge kind of cultural issue on campus. So in both those times I've kind of been like, "Okay, let me get together with... you know—let me go to the Women's Center; let me get together with Broad Recognition. Let's figure out what we're gonna do. You know are we gonna make a zine? Are we gonna help people who are organizing protests?" It felt like I had a community, and I think just... even though obviously I was back in New York City, that's where my family is and that's where I grew up... I just felt not very tapped into what was going on. And you know I was going to marches and that sort of thing, but it was... it was hard... I just didn't necessarily feel like I had that community. At the same time, I think I was also just grappling with what it means to do a 9-to-5 job where you're kind of exercising mainly one skill set, and I was missing the creativity and the ownership that I had been able to exercise more in my leadership on campus the year before. And so, I ended up quitting my full time job probably like 7 or 8 months after Trump was inaugurated and that was not the reason, but I do think that it had a little bit to do with it. I also, while I was working that full time

¹¹ In reference to the 2016 United States presidential election, in which the Republican candidate Donald Trump was elected to serve as president until 2021. ("United States Presidential Election of 2016." Britannica. Accessed June 29, 2022. <https://www.britannica.com/topic/United-States-presidential-election-of-2016>)

¹² Donald Trump is an American politician and businessman who served as the 45th president of the United States from 2017 to 2021. He is affiliated with the Republican Party and is well known for his conservative, populist, and nationalist ideologies. ("Donald J. Trump." The White House. Accessed July 11, 2022. <https://www.whitehouse.gov/about-the-white-house/presidents/donald-j-trump/>)

¹³ Refers to the title of the men's NCAA DI basketball tournament that begins around mid-March. It is single elimination, involving 68 teams in total. Also sometimes used to refer to the women's tournament, although not officially titled as such ("March Madness." Dictionary.com. Accessed April 8, 2022. <https://www.dictionary.com/e/historical-current-events/march-madness-meaning/>)

job, I was dealing with some mental health issues, and I really started to lean into wellness culture in a way I had not ever before. I've always been athletic. I've always liked team sports. In high school, I started going to the gym—there was a nice gym at my high school that I started going to at one point—and really was like, “Wow, this is an amazing way to spend time.” So I've always found some level of empowerment through fitness and that starting for the first time to lean into that culture more and in doing so I was getting some of the benefits of you know of daily meditation and that sort of thing but I was also realizing just how toxic that culture could be, and just seeing the ways that sort of wellness was white-washed¹⁴ and really this corporate aspect of wellness culture was being emphasized. And so, I remember a lot of times talking to friends about [fitness] classes I was taking and a lot of my friends being like “I would never feel comfortable even stepping foot in that studio.” And just being very aware of the privilege I had as a cisgender¹⁵ passing¹⁶ white, thin young person to walk into these spaces, and yeah it might be uncomfortable for me because they might not fully understand who I am and there might be triggering diet language and that sort of thing and being very different from the experience of let's say—you know a plus size friend who was showing up to a spin class despite having taken hundreds of spin classes before and being tutored how to use the bike every single time just because of the way she looked, right? So just started to feel both like I wanted to kind of do something of my own, build that community, start to tap into some sort of feminist, queer community in New York City a little bit more but also feeling like there's a real problem with a wellness industry that is really only serving people who maybe need it the least, right? And is also pulling from these traditions that are really rooted in BIPOC¹⁷ communities, in LGBTQ communities, in feminist communities, even just the concept of self-care, right? And sort of capitalizing on that concept. Sorry it's like storming here [laughter]. But... so wanting to sort of interrogate that and really just wanting to create [uses air quotes] “safe spaces” as we called them at the time for people like those friends who didn't feel comfortable coming to these classes and for me honestly to explore some of these ideas and explore them in an explicitly political context. So, I think the first event that I ever ran with Body Politic was in April of 2018 and it was a

¹⁴ Whitewashing in media is the practice of casting white actors in movies as opposed to non-white actors, especially in cases where the character is not supposed to be white. The concept also includes other scenarios such as “preferring” white actors for undetermined reasons. (Gillespie, Claire. “What Is Whitewashing, and Why Is It Harmful? Here's What Experts Say.” Health. Accessed July 11, 2022. <https://www.health.com/mind-body/health-diversity-inclusion/whitewashing>)

¹⁵ Cisgender refers to someone whose gender identity matches their gender assigned at birth, according to societal standards. The opposite of transgender. (Shaw, Susan M., and Janet Lee. 2020. “Systems of Privilege and Inequality.” *Gendered Voices, Feminist Visions: Classic and Contemporary Readings*. 7th edition, p. 46)

¹⁶ In this case, “passing” refers to the idea that the interviewee still benefits from cisgender privilege because other people perceive them as a cisgender person, despite them not actually being one.

¹⁷ The acronym BIPOC stands for “Black, Indigenous and people of color.” (Garcia, Sandra E. “Where did BIPOC come from?” The New York Times. Accessed June 29, 2022. <https://www.nytimes.com/article/what-is-bipoc.html>)

conversation on self-defense and physical empowerment in the age of Trump. So, we had... it was like very political, and we heard from mixed martial artists, boxing instructors, people who were doing a range... self-defense instructors, and sort of how they were thinking about this concept of feeling safe in your body as tied to also... learning how to fight... learning how to fight back physically. Learning how to defend yourself, or even just feeling strong. So I think that Body Politic has obviously evolved a lot since that first event but that was really kind of the goal going into it. Was to both give people a space, find a community myself, exercise some of this creativity that I had felt I didn't have an outlet for, but then also to feel like we were able to really interrogate and get deeply into these questions of like health at every size, and sexuality... the connection between sexuality and sensuality and movement. You know—all of this stuff that I felt like was on the edges of what was being discussed in the mainstream but was usually stigmatized [unclear] for like doing yoga class and Trump has just been elected but like no one was acknowledging that. You know what I mean? [laughter] So... that was kind of in that vein a little bit, I think. [nods]

AD: So interesting. In some ways it seems so inherently intersectional¹⁸ to sort of bring things together in simultaneity that could otherwise be argued are disparate but are—you know—making the case for them being intensely relevant. Was that something that was explicitly in your mind?

FL: Yeah. [nods] Yeah, I mean we talked a lot about like in the framing of these events and the content we were creating. We did talk a lot about the idea of the personal being political but also the idea that that means something different for each person—even as something as small as arriving at a meditation class—we're all arriving at that class with a different set of identities, personal experiences, emotional baggage, and just basically that that needs to be acknowledged in some sense. So I think, yeah, a lot of it was about trying to create some intersectionality within this... kind of [unclear] wellness industry at that place and time in 2018... Now there are a lot of amazing offerings doing exactly this, you know, trying to look at wellness through a political lens or create community wellness groups around a very

¹⁸ Intersectionality is the acknowledgement that different social categorizations (e.g. race, class, gender, sexuality, ability, etc.) are interconnected to create overlapping systems of privilege and discrimination that marginalize each individual in a unique form. The term was first introduced by Professor Kimberlé Crenshaw in 1989. (Taylor, Bridie. "Intersectionality 101: what is it and why is it important?" Womankind Worldwide. Accessed May 17, 2022. <https://www.womankind.org.uk/intersectionality-101-what-is-it-and-why-is-it-important/>)

specific identity. There are hype clubs for Black and Latinx¹⁹ folx in Los Angeles.²⁰ There are boxing studios for trans²¹ folx. That stuff was really only just getting started at the time. So I think a lot of what we were trying to do is identify those offerings and make them visible and that was a lot of it as well.

AD: And when you had that first meeting in April of 2018 was it already called Body Politic... Or did that name...?

FL: [nods] Yeah, that was kind of... so the first thing I did I think was in March of 2018 I had a brunch at my house, and I invited a lot of friends that I had had these conversations with before. So, the people that would be texting me going like, "I love... like I hate that I love this thing that I bought from Goop."²² You know? [laughs] Like that sort of conversation. Or the people like, "I want to go to that spin class, but I just don't feel comfortable." Or that sort of thing. So I invited a lot of those people to my house and I kind of threw this... this name around. Like, what do you think about this name Body Politic? What do you think of when you hear that? And people were saying that they thought of a group. That they thought of a political entity with power... but also that it reminded them of kind of the ways in which their bodies were inherently political both by their choice but also politicized by society. You know, whether that's because you're living in a Black body, or a plus-sized or fat body, or a disabled body, or a body with a uterus or something like that. So, I think... I think that was a name that was percolating in my head and then I sort of tested it out on... on you know...

AD: on your own focus group?

FL: Yeah, yeah. And a lot of my friends brought friends to that brunch too which was... which was fun, so it was kind of already expanding a little bit at that point.

¹⁹ The term "Latinx" is an updated and contemporary version of the term "Latina" or "Latino" in reference to people of Latin American descent. It was conceived initially to include individuals who did not identify with the gender binary. ("What is 'Latinx'?" C& América Latina. Accessed July 11, 2022.

<https://amlatina.contemporaryand.com/editorial/latinx/>)

²⁰ Los Angeles is the second-largest city in the United States after New York City. It is an important metropolitan area in the state of California, characterized by its ethnic and cultural diversity, as well as its contributions to the film industry. ("Los Angeles." Wikipedia. Accessed July 11, 2022.

https://en.wikipedia.org/wiki/Los_Angeles)

²¹ Trans, or transgender, refers to someone whose gender identity does not match their gender assigned at birth, according to societal standards. The opposite of cisgender. (Shaw, Susan M., and Janet Lee. 2020. "Systems of Privilege and Inequality." *Gendered Voices, Feminist Visions: Classic and Contemporary Readings*. 7th edition, p. 46)

²² A company founded in 2008 by Gwyneth Paltrow, that focuses on wellness and lifestyle products and promotion. It is a private business in the publishing and internet retail industry. ("Goop (company)." Wikipedia. Accessed April 8, 2022.

[https://en.wikipedia.org/w/index.php?title=Goop_\(company\)&oldid=1078647454](https://en.wikipedia.org/w/index.php?title=Goop_(company)&oldid=1078647454))

AD: Right. And were those friends then part of the early beginnings of the group? Have they... stayed? Or have some folks moved on?

FL: Yeah so, I think a lot of them all were part of the early beginnings, because also at the beginning I was just basically... invested like... Honestly, a few hundred dollars on having a first event and just like paying for the space and was charging for donation based tickets so you know anyone can come just pay what you can, and I would just put a call out. I would send out an email, “does anyone want to help me staff this event? Will someone help me make nametags? I need someone to help pour the wine...” or whatever it was. And a lot of these people were really excited about doing that because, like me, a lot of them were working 9-to-5 jobs... entry level jobs... that weren’t that exciting, and doing something like that on the weekend was fun. So, a lot of them are still involved. I’m trying to think how many are still involved in some capacity. I mean, Body Politic has changed a lot since then. I think one of the people who has really been a part of it from the beginning is my friend, Sabrina, who is also the person who infected me with COVID and co-founded the support group with me. And so we’re kind of just partners in creative stuff in general and so she’s also been a sounding board for me and even now that she’s a little less involved in the day-to-day activities of Body Politic we still—as am I because I’ve stepped back from kind of leading the group for several reasons—but she remains like, a very active partner in thinking through that stuff. But the most amazing thing that happened with Body Politic during the pandemic was just meeting so many new people through it and basically identifying the new leaders of Body Politic: All people that I met online, most of them I have never even met in person. So... yeah. [nods]

AD: Wild. Maybe that would be a good segue to talk about that... watershed moment. How Body Politic transitioned into a space for COVID-19 and supporting those with long COVID.

FL: Yeah. Yeah. [laughs]. Yeah, I’ll rewind to kind of like... March 1st, 2020.

AD: Let’s do it. [laughs]

FL: [laughs] Yeah, wow. What a time. So we started hearing about the Coronavirus obviously, and I think at the point that it hit Italy and was really devastating Italy kind of at the end of February it started to become clear that probably COVID was going to come to the United States in some form. I started to talk to Sabrina and other people at Body Politic about what we should be doing because it was clear that we weren’t going to be throwing a huge, live event like we usually did and so we were talking about the idea of maybe

creating some like Zoom²³ support groups for people. Actually... we were like maybe we should create groups for the two groups we were talking about creating was like an Asian affinity group for people experiencing harassment and violence, and the other group that we were talking about creating was a group for immunocompromised people: cancer survivors, folks that might be at greater risk of COVID, because, at this time we were still very much being told that if you were young and generally healthy or otherwise healthy you really didn't have to worry about COVID. It would be maybe a mild cold. And you know, I was thinking that my main role would be as an ally to the elderly and the immunocompromised and that sort of thing. And then we had this meeting on March 10th. So, Sabrina came over to my apartment on March 10th and we basically met to just discuss the future of Body Politic and we were talking about the pandemic a little, but we were also like talking about problems [unclear] with the campaigns we wanted to get going... we were zooming with all of these people involved in Body Politic in different states to talk to them about kind of what they think we should do in this next year. And of course, COVID was kind of this backdrop to everything we were talking about and so there was this little moment of "what if?" But really no one thought at that... I mean, the first case of community spread in New York was only confirmed—you know—a few days before that. So... while we were in my apartment Sabrina got an email from her work that they wouldn't be... that they would be shutting everything down and that she didn't have to go back to work the next day. And then, a few hours later—and this was after we had sat next to each other on a couch like talking for hours at screens and also cooked and eaten dinner together—Sabrina got really pale and she suddenly was like, "I don't feel well. Like I feel really weird." And, you know, of course both of us thought, we were like, "just in case"—she was supposed to sleep over at my house that night—we were like "just in case, go home right now, and rest up and we'll touch base later." Of course, there was that thought, "could it be COVID?" but it really wasn't on anyone's radar to that extent. So, she went home and then three days later I developed a headache and low fever basically. So that was March 13th that I became symptomatic. In the week that followed she... we both got significantly worse, and we both were very, very, very sick. And it was not something that I was seeing reflected in any of the mainstream news coverage of the pandemic. The difference in our symptoms was not necessarily severity and I kind of drive this point home because I think that there have been some weird categorizations of mild versus moderate versus severe. The difference was that I had more severe shortness of breath than she did. So she was still dealing with a wide array of very intense symptoms that were super debilitating but because I had that severe shortness of breath and also because I had a primary care physician (PCP) in the city who I had known for years, I was able to get through to her and actually talk to my PCP and tell her what was going on and she said that I needed to go to the Emergency Room (ER) if

²³ Zoom is an online video-call, chatting, and webinar platform that became particularly popular and widely used during the COVID-19 pandemic.

my shortness of breath continued to get worse. Sabrina, meanwhile, and I think this story just really conveys kind of how differently it can go for different people, was trying to get through to doctors via telehealth appointments. Not having success. Sabrina's family lives in other countries. She did not have a trusted doctor here, and she basically had to manage all of her symptoms on her own from home. Meanwhile... I was hospitalized on March 16th, I believe? 16th or 17th... I spent one night in the ER. I was [unclear] fine. I... the hospital was... not a good place to be at that point in time but it got much worse, so I ultimately did get lucky. I also got really lucky that I was hospitalized because so many people were turned away from the hospital at that time and I've since read stories of Black women my age who were told it's anxiety and died of this virus at the same time so I think my privilege as a white person... I wore my Yale sweatshirt because I was like honestly anything I could do to like wave a flag of like "I'm an important person." I know how the ER works. I know that like here I am at the time I was on a New York state health insurance plan that was a step above Medicaid.²⁴ I was a gig economy worker.²⁵ I didn't have family members that were doctors or on the board of hospitals, but I got really lucky. So, I managed to survive on supplemental oxygen. They didn't have to put me on a ventilator. When I got home, they discharged me after like two days in the hospital. They were a little unsure whether or not to discharge me, but I wanted to go home and one of the nurses said to me, "this is not the place to be." When I got home, I thought that I would be tired and that it may take me a little while to recover but what I never imagined was I did not think there would be new symptoms that would show up. Especially because at the time the CDC²⁶ symptom list was basically respiratory issues, fever, and maybe headache. There was nothing on there about GI²⁷ issues... or any of the many other things that I began to develop. So, the one piece of... there was no information. You'd google, "COVID gastrointestinal issues" and you'd get like one story in some weird publication about someone on a cruise ship who had an upset stomach. It was not... it was very hard to find information. So Sabrina and I really started kind of staying in very close contact at that point. Texting each other about all of our new symptoms. And soon as I was able to speak again because my shortness of breath made it

²⁴ Medicaid is a federal initiative that provides assistance with healthcare costs for low-income citizens in the United States. ("About Us." Medicaid.gov. Accessed July 13, 2022. <https://www.medicaid.gov/about-us/index.html>)

²⁵ Gig economy workers are usually independent contractors or freelancers who provide flexible on-demand services for companies rather than engaging in a standard, full-time work arrangement with the employer. ("Gig Economy." Investopedia. Accessed August 3, 2022. <https://www.investopedia.com/terms/g/gig-economy.asp>)

²⁶ CDC stands for Centers for Disease Control and Prevention. It is a national public health initiative that works to protect the United States from health threats and risks. ("CDC Organization." Centers for Disease Control and Prevention (CDC). Accessed July 13, 2022. <https://www.cdc.gov/about/organization/cio.htm>)

²⁷ GI refers to gastrointestinal issues, which affect the gastrointestinal tract. Diarrhea, nausea, and food poisoning are some examples. ("Gastrointestinal Diseases." Cleveland Clinic. Accessed July 13, 2022. <https://my.clevelandclinic.org/health/articles/7040-gastrointestinal-diseases>)

very difficult to speak for about four or five days... we had a FaceTime conversation.²⁸ And it was like looking in a mirror. Like we both felt freaked out that we were both dealing with these things, but it was the most validating... I mean she was getting gaslit by people in her life. I was emailing my doctor, "could this be...?" COVID symptom? I have no idea. I had been told at the ER... that GI symptoms might be food poisoning because you can't have that with COVID... so you know, we were just talking to each other. "Did you lose your sense of smell?" "Yes! I lost my sense of smell." "Are you able to keep food down?" "No!" "Me neither!" You know... "I'm getting hives and rashes." "Me too." And we were sleuthing. She was sending me a Twitter thread²⁹ by somebody else who had lost their sense of smell. It was just this moment of like, "Okay, the CDC is unfortunately not going to have the answer to this right now and my doctor might not even have the answer to this right now but by talking to other people in the same situation I might actually be able to find information." Something that happened in this time period that really helped in terms of information gathering was that I wrote an Op-Ed³⁰ like two days after I was discharged from the hospital. I wrote an Op-Ed in the New York Times³¹ just about being young and being hospitalized. Because...

AD: I read that... I remember that coming out...

FL: Okay yeah. So I had posted on my Instagram³² that I had tested positive like right after I tested positive. It seemed like one of the easiest ways to get the word out to everyone that I had potentially been in contact with and also just update people because you're exhausted, it's hard to text everyone individually. Obviously, I was still texting close contacts individually, but... the reaction to the post really surprised me because people had so many questions. And I realized, "Oh I have actually a little bit of a glimpse into this thing that

²⁸ FaceTime is a video and audio call service developed by Apple. ("Use FaceTime with your iPhone, iPad, or iPod touch." Apple Support. Accessed July 13, 2022. <https://support.apple.com/en-us/HT204380>)

²⁹ Twitter is a social media platform rooted in short posts under 280 characters, referred to as tweets. A thread is a series of multiple interconnected tweets made by one single person. ("How to create a thread on Twitter." Twitter Help Center. Accessed July 13, 2022. <https://help.twitter.com/en/using-twitter/create-a-thread/>)

³⁰ "Op-Ed" is short for "opposite the editorial page" and usually refers to an article written by an author or a group of authors to reflect their own opinions. In print media, these articles were often published opposite the editorial page, hence the name. (Tapia, Allena. "What Is an Op-Ed Article?" The Balance Small Business. Accessed July 13, 2022. <https://www.thebalancesmb.com/oped-what-is-it-and-how-to-write-it-1360714>)

³¹ The New York Times is one of the most popular American newspapers, having won over 132 Pulitzer Prizes and obtained international readership. ("The New York Times." Wikipedia. Accessed July 13, 2022. https://en.wikipedia.org/wiki/The_New_York_Times)

³² Launched in 2010, Instagram is a photo and video sharing platform that remains one of the most popular social networks in the world with around one billion active users. ("Distribution of Instagram users worldwide as of April 2022, by age group." Statista. Accessed July 13, 2022. <https://www.statista.com/statistics/325587/instagram-global-age-group/>)

everyone is worried about, and nobody knows about which is what happens if you get a case of COVID that is so bad that you have to be hospitalized.” So, I felt like, okay, let me write something to tell people more about this and sound the alarm that people my age that we may not be as protected as we think and that piece went... you know... viral.³³ Weird choice of word there [laughter]. And so, I started getting DMs from tons and tons of other COVID patients all over the world saying like, “I’m in the same situation.” There were people in... I remember there were people in France, London, Germany... I was talking to people in California. There were a lot of people in New York that I was talking to. There was someone in Chicago³⁴ that was DMing³⁵ me. And in the days after being discharged from the hospital it was actually very nice to have all of these people that kind of were going through something so similar, but it was also very difficult to communicate with each of them one on one. One, because there was a massive amount of responsibility to each of them and I was exhausted dealing with the symptoms. I was talking to Sabrina about this when we were Facetimeing, and we were like “what if we just put them all in a group chat together and like started this as a support group and you know what Body Politic is kind of the perfect platform to promote this on and I bet it’ll be a helpful resource.” That was maybe March 20th that we put them all in the chat together.

AD: It happened so fast.

FL: It happened *so* fast. Yeah... yeah. And that first chat I still have... I still keep in touch with a lot of those people. A lot of them have made full recoveries. Some of them still have taste and smell issues, but a lot of them have made full recoveries. But I think we’re like very bonded, as kind of... you know, we call ourselves [does air quotes] “first wavers.” Those of us who got sick in February, March, April, May, and some, some people obviously got sick in January as well. And so, it was... it was really meaningful to kind of be there with all of them, and talk with them, but, then I started to notice that they were not getting better. And a lot of them had had a more mild initial case than I had so there was... you know... a guy in the group who said, “I have only had a fever of 100 degrees but I’ve had that 100 degree fever for three weeks... every single day for three weeks.” And he was like, “I can’t get any care because if I go to acute care or I call a doctor they say, ‘well what are

³³ The expression “going viral” in relation to social media means spreading quickly or becoming very popular in a short period of time. This can be achieved through features such as likes, comments, views, and especially sharing. (“What Does Going Viral Mean?” Vertical Rail. Accessed July 13, 2022. <https://www.verticalrail.com/kb/what-does-going-viral-mean/>)

³⁴ Located in the state of Illinois, Chicago is the third-most populous city in the United States, right after New York City and Los Angeles. The city has a large and important urban area, as well as multiple tourist attractions such as the Navy Pier, the Millennium Park, and the Cloud Gate sculpture, popularly referred to as “the bean.” (“Chicago.” Wikipedia. Accessed July 14, 2022. <https://en.wikipedia.org/wiki/Chicago>)

³⁵ Sending a direct message, or private message, to someone on social media.

your symptoms?’ and I say, well I have this fever. They’re like ‘well it’s only 100 degrees, it’s nothing to worry about.” So I started to feel like... This is also at the same time that my symptoms are morphing in this bizarre way that I had never experienced before. Where now I have a stuffy nose, and a sore throat, and sinus pain which I didn’t have. Suddenly I’m feeling light and sound sensitivity. I’m getting these super intense headaches that I think are migraines. So, I was like there is something more here that we are not really talking about which is what happens after that initial, you know, week of having COVID, and at this point the WHO³⁶ was still saying it should only take 2-4 weeks to recover from COVID. So I wrote this second Op-Ed, really thankful to my New York Times editor, who’s amazing, who actually works on the gender section of the Opinion section for publishing this second Op-Ed about what COVID recoveries look like. I don’t think she realized at the time what a big impact it would have. I didn’t either. I remember even telling my parents I was writing, and they were like, “Oh that sounds kind of interesting.” [laughs] And in the piece I linked to the support group, you know, sign-up form. Because as of March 26th we’d kind of shared that we had this support group going. It was an Instagram chat. We’d like shared it on our Body Politic Instagram. A few more people signed up. We had like 30 people in the group at the point. And I interviewed a bunch of the people in that group for this article. So the article came out on April 13th, exactly a month after I got sick. And within like 24 hours of that article going up over 2,000 people had signed up for this support group. And so I was like looking at the google form—it was just every second there was somebody new signing up and it was all over the world. Again, there’s a lot of these hotspots. A lot of people signing up from London³⁷ and NYC and it was just this like really weird feeling of... you know... I felt at the same time incredibly stressed. Like what the hell am I going to do with all of these people? They can’t all fit in an Instagram chat. Like I don’t even know what I’m doing. And I also felt so worried and concerned that there was this many people dealing with these long term symptoms, but it was also very validating. Because when I wrote that article, I was like, “This seems to be a problem but I’m not really sure, and is it just... you know, am I making it up? Is it just a problem with me? Am I not pushing myself hard enough to recover?” And so that really confirmed that, no, this is a widespread issue and something that needs to be talked about more. And that article was really kind of the first piece in a major, mainstream news publication that talked about what we now call long COVID. People dealing with these long term symptoms and people specifically who had not

³⁶ The World Health Organization (WHO) is an agency within the United Nations, concerned with promoting health initiatives and guaranteeing the well-being of people all around the globe. (“About WHO.” World Health Organization. Accessed July 14, 2022. <https://www.who.int/about>)

³⁷ London is the capital city of England and the United Kingdom, as well as one of the major global cities in the world. It is highly regarded as an influential cultural center, with major contributions to the arts, science, technology, fashion, among many others. (“London.” Wikipedia. Accessed July 14, 2022. <https://en.wikipedia.org/wiki/London>)

been on ventilators, because of course, we include people with kind of post-ICU³⁸ syndrome within the long COVID umbrella, but I think that a lot of the long COVID stories we hear today are about people who had a more mild or moderate case and have kind of these multi-systemic issues afterwards. So, I think that... I'd love to say that that blew the lid off long COVID and then everyone started talking about. Not quite, it took a while longer after that; I had to write many more articles. Ed Yong,³⁹ I think was really helpful in getting it on the map he wrote about it in the Spring. But yeah, from there we kind of... we moved to WhatsApp⁴⁰ because we exceeded Instagram's chat limitations. And we were on WhatsApp for about... I don't know, maybe six hours before we exceeded WhatsApp... Sorry I think it cut out. But we were on WhatsApp for like maybe 6-10 hours before we exceeded WhatsApp's chat limitation, and even on WhatsApp people were also like, "I can't follow this conversation," because people were writing every second. So that was kind of where we got the idea for a Slack⁴¹ because we knew we could have these different channels and there was no member cap. I had never really used it before because I... I wasn't working like corporate jobs [laughs] so I had to learn how to use Slack overnight, but a lot of other people did too. And that's where we've been ever since. And... I think we've had close to 35,000 people sign up for this group over the whole pandemic. That's not the number that is currently in the group; there's 11,000 people or 4,000 people. Yeah, because some of the people who sign up. You sign up through google form and then you get a link so some people, you know, don't choose to join. And then in some cases also, we keep the group just for patients and caregivers. So we've had like journalists sign up; we don't invite them into the group. That sort of thing. You have to kind of explain why you want to join. So that's kind of a basic summary of just the support group, and then that support group ended up becoming really like a hub for long COVID advocacy. All of these other projects grew from it. The Patient-Led Research Collaborative⁴² is one of the most widely recognized, which is patients conducting research on long COVID. They are also all scientists and people with

³⁸ ICU stands for intensive care units, a designated ward in hospitals and healthcare clinics that is reserved for critical patients and those who need intense monitoring. ("Intensive care." National Health Service (NHS). Accessed July 14, 2022. <https://www.nhs.uk/conditions/intensive-care/>)

³⁹ A Pulitzer Prize-winning science journalist for *The Atlantic*, known for his writing on the pandemic ("Ed Yong." Wikipedia. Accessed April 8, 2022. https://en.wikipedia.org/wiki/Ed_Yong)

⁴⁰ WhatsApp is an instant messaging, phone call, and video call service owned by Meta (previously Facebook) and used by over 2 billion people worldwide. (Dean, Brian. "WhatsApp 2022 User Statistics: How Many People Use WhatsApp?" Backlinko. Accessed July 14, 2022. <https://backlinko.com/whatsapp-users>)

⁴¹ A business communication platform that offers chat rooms for different topics, private groups for messaging, and offers the ability to directly message others through the app. ("Slack (software)". Wikipedia. Accessed April 8, 2022. [https://en.wikipedia.org/w/index.php?title=Slack_\(software\)&oldid=1080258416](https://en.wikipedia.org/w/index.php?title=Slack_(software)&oldid=1080258416))

⁴² The Patient-Led Research Collaborative is a research initiative started by a group of Long COVID patients in the Body Politic support group, which focuses on researching Long COVID from the perspective of disability justice. Their research spans various areas including machine learning, biomedical research, and public policy, among others. ("About the Patient-Led Research Collaborative." Patient-Led Research Collaborative. Accessed July 14, 2022. <https://patientresearchCOVID19.com/>)

backgrounds in science and research which is something that sometimes gets ignored. But they also have an intimate knowledge of long COVID, and they define that expertise quite broadly, so you don't have to have super high level degrees. And there's a lot of peer teaching that goes on there which is very cool. And then obviously there's been a lot of direct policy attempts at advocacy with policy makers and health agencies and we were meeting regularly with the CDC and the WHO and the NIH⁴³ and the POTUS COVID Equity Task Force.⁴⁴ So I think it's really a combination of that sort of thing happening. There have been letter writing campaigns, meetings with the WHO, there's a UK based group called Long Covid SOS,⁴⁵ which grew out of Body Politic and has a WhatsApp and focuses on the United Kingdom and Europe as well. So that's kind of a broad overview.

AD: Super helpful. The mapping was really illuminating, and I'm curious... Are you part of all of these branches that have grown off of that? I'm trying to imagine how you manage that time and if that is part of... You mentioned earlier that you've stepped away in some form and that is part of managing...

FL: Yes, so until I would say like June of 2021, I was pretty involved in most of these things. My involvement in the Patient Led Research Collaborative was generally just as an editor. I do not have the background as a researcher to be like doing data analysis or that sort of thing. But I often helped them look over their surveys and just make sure the language was inclusive for our communities, and sometimes help them edit some of their reports and stuff. But less involved in that, although I'm close with all of the people who run that initiative and they're doing amazing work. I was pretty involved with a lot of the advocacy work. I attended a lot of those meetings with the CDC, and the NIH, and the WHO. I would say up until June, and a lot of my focus as well was on communications. I was on and off directing the social media for the past year during the pandemic with a lot of help from other amazing people. Also, just managing the media relationships because we were getting so many press requests and it's very... It's a very kind of touchy and difficult thing to navigate how to connect a group of vulnerable patients with journalists who do not

⁴³ NIH stands for National Institutes of Health, a biomedical research agency within the U.S. Department of Health and Human Services whose goal is to promote health and improve quality of life for all Americans. ("About NIH." National Institutes of Health (NIH). Accessed July 14, 2022. <https://www.nih.gov/about-nih>)

⁴⁴ Established early 2021 by the Biden-Harris Administration, the Presidential COVID-19 Health Equity Task Force aims to reduce social inequities that were aggravated by the pandemic through supporting high-risk communities and vulnerable populations in the fight against COVID-19. ("Health Equity Task Force." U.S. Department of Health and Human Services, Office of Minority Health (OMH). Accessed July 14, 2022. <https://www.minorityhealth.hhs.gov/omh/browse.aspx?lvl=2&lvlid=100>)

⁴⁵ The Long Covid SOS campaign was founded in the UK with the goal of addressing the needs of those struggling with the effects of Long Covid and advocating for more extensive research on the subject, as well as raising general awareness about the condition in order to prevent discrimination. ("Our Story." Long Covid SOS. Accessed August 3, 2022. <https://www.longcovidosos.org/our-story>)

understand exactly the dynamics that are going on. So, trying to figure out ways to streamline that system. Make it better; make it feel safer for patients. And then I've also done a lot of work just educating the media about covering long COVID. I've written guides to interviewing COVID patients. I've written guides to writing about long COVID and related illnesses. I've done a couple of workshops. We had a media training workshop in our support group actually at one point: GLAD.⁴⁶ I had a friend... Sabrina's girlfriend worked at GLAD. [inaudible]... for people in our workshop who wanted to do advocacy work. But I stepped back from a lot of this in June and July for a combination of reasons. The first was just that I'm not the same person I was before I got COVID, and I still have some lingering health issues that I have to manage. But I am not... my life is not severely altered by my long COVID experience anymore. I don't experience daily debilitating symptoms, and I haven't really since I got the vaccine. My first three months were quite difficult when I first got sick, and then after that I was intermittently ill. I actually had a lot of menstrual issues related to COVID. The vaccine offered quite a bit of relief from some of those symptoms, and it has had therapeutic qualities for some people. So I just felt like the President is kind of the spokesperson of the organization and I felt like the face of the organization and the face of this patient led long COVID movement ideally should not be a white non-disabled person. So the person who is running Body Politic now is someone who I connected with very early on in being sick. She was a member of the support group. Her background is in activism and advocacy and she's a Latinx organizer living in Los Angeles who has, I think, dealt with more of the long term symptoms than I have. So I just wanted to position myself a little bit less in that spokesperson role after kind of mostly recovering. But also, to be honest there were financial issues for me. I am... I hadn't worked... I hadn't really prioritized my financial situation for most of the pandemic because I was just so grateful to have a little bit of savings that I could live off of while I was at my sickest. And running Body Politic was incredibly fulfilling but it was not something I was personally making money off of. The donations that we got went straight back into managing the subscriptions for different things and compensating the few members of our team who were doing more project management and that sort of thing. It got to a point where I also had to take a like good, hard look at my life and realize that I was putting myself and members of my family perhaps not in the best situation by not prioritizing my own finances a little bit more. So, I'd say it was a combination of both those things. So I'm still on Body Politic's board and I still volunteer hours with them on a weekly basis when I can, but I'm... I would say less in a leadership role of the organization right now.

⁴⁶ Stands for GLBTQ Legal Advocates & Defenders. This is a US non-profit that works through litigation and public policy advocacy to discontinue discrimination based on gender identity, sexual orientation, and HIV status ("Mission and Values." *GLAD*. February 1, 2022. Accessed April 8, 2022. <https://www.glad.org/about/>)

AD: That makes a lot of sense, and I'm really glad to hear that you're feeling better, if not fully recovered, and that it is not impacting your life on a day-to-day basis although maybe it is in some ways and I'm sorry that you've had to navigate all of that.

FL: Thank you.

AD: I'm curious about sort of the intersectional dimensions of your experience with Body Politic and with long COVID maybe more generally. If we could tease out sort of the gender dimensions, the race, the class dimensions... that may or may not have emerged immediately or over time.

FL: Yeah. Yeah, definitely. So, I think that the... personally the most significant political evolution that happened for me during the pandemic was just fully coming... I had always been aware of the disability justice movement and had some level of education in that, but I honestly don't think I really understood it until I myself got sick and witnessed this mass disabling event. And so I think the framework of disability justice has been really important throughout this pandemic for me. Just in terms of recognizing both the fact that what's happening with long COVID is not new. That there have been people that have been largely neglected by medicine in science who have experienced post-viral and post-infectious illnesses that have... that we don't have a lot of answers on. Not because they are inherently mysterious but because the research, the funded research, hasn't necessarily existed. And also understanding that a big part of why that may be is who these illnesses affect. So, I think a real mentor... there have been a lot of mentors for me throughout this past year. Many, many people from the ME/CFS community.⁴⁷ People with myalgia encephalomyelitis [unclear] has been a really influential person kind of in my own political journey, and I think her documentary, "Unrest,"⁴⁸ paints a very clear picture of how the connection between gender and medical sexism and ignorance... medical ignorance about these illnesses. Similarly, I have connected with a lot of folks who were involved in "Act Up."⁴⁹ And it's been really helpful learning more... You know, this is something I studied in school

⁴⁷ Myalgic encephalomyelitis (ME), commonly known as chronic fatigue syndrome (CFS) or ME/CFS is a disease characterized by dysfunctional and often disabling bodily systems, causing overwhelming fatigue, among other symptoms. ("What is ME/CFS?" Centers for Disease Control and Prevention (CDC). Accessed July 11, 2022. <https://www.cdc.gov/me-cfs/about/index.html>)

⁴⁸ *Unrest* is a 2017 documentary by Jennifer Brea, told from her own perspective as an ME/CFS patient who has her condition neglected by doctors. ("Synopsis." *Unrest*. Accessed July 11, 2022. <https://www.unrest.film/>)

⁴⁹ Stands for AIDS Coalition To Unleash Power. A non-partisan political group dedicated to ending the AIDS pandemic through meetings with government officials, distributing medical information, and protests, among other means ("What is Act Up?" *Act Up* NY. May 13, 2021. Accessed April 9, 2022. <https://actupny.com/contact/>)

and obviously I was born in the 90s in New York City, so AIDS was certainly a backdrop for much of my childhood and upbringing. But, just to learn more about the different organizing techniques, and as well... I think that both ME/CFS and the activism that has happened there and the HIV/AIDS activism, there are so many lessons to learn from that, and especially with HIV/AIDS there are some clear pitfalls to avoid. And I know that my own personal story got a lot of attention and I know that it was kind of helpful to use my face and my story as a way to get eyes on this issue, but I also feel weird about it because I know that I got that attention because I was a Yale graduate and because I had a quote unquote, "fit and active and healthy." So, I've been very concerned from the beginning about the erasure of people with... you know, who were disabled prior to getting COVID or were chronically ill prior to getting COVID. There's been a... so often when there's a story of someone dying of COVID or developing long COVID the first questions from commenters is, "Well, did they have a preexisting condition?" And so, just... which is such a ridiculous question when we live in a country where the majority have preexisting conditions. So, thinking about that, thinking about, "Well, what would this story have been like if I wasn't white?" You know, I have friends that I've met through the long COVID community that got sick at the same time that I did that did not get the same care that I got. I have a close friend now, who is a Black 39-year-old woman in Baltimore, who had more life experiences than I did, more experiences navigating these systems, but was not treated with the same respect that I was. Similar thing with Angela Vasquez in Los Angeles who's running Body Politic. And I think we saw that with HIV/AIDS too, right? We had these white men, white male [unclear] I think we're back?

AD: There was a moment where I thought I might lose you, but you're back.

FL: [laughs] yeah. Yeah, so just looking at HIV/AIDS as well, kind of thinking about how a lot of the movement initially was defined by these public faces like Peter Staley⁵⁰ and Larry Kramer⁵¹ and these white, educated men who were really effective at getting eyes on the issue by sort of... in the case of Peter Staley, like this could be your son, you know? A handsome, white guy that you wouldn't necessarily know is gay and he has this illness, and you could have it too. But, in writing about how to cover long COVID and COVID, I have interviewed [unclear] I have covered the HIV/AIDS epidemic, and some of the things that have come to mind, or that have come to light are—it feels like there are such parallels with

⁵⁰ A political activist in the US, often cited for his work for HIV/AIDS through his membership to ACT UP and founding of both the Treatment Action Group and [AIDSmeds.com](https://en.wikipedia.org/w/index.php?title=AIDSmeds.com) ("Peter Staley." Wikipedia. April 3, 2022. Accessed April 9, 2022. https://en.wikipedia.org/w/index.php?title=Peter_Staley&oldid=1080743605)

⁵¹ An activist for gay rights, playwright, author, producer, and public health advocate. He was known for co-founding the Gay Men's Health Crisis, the largest private organization aiding those with AIDS, and for founding ACT UP ("Larry Kramer." Wikipedia. Accessed April 9, 2022. https://en.wikipedia.org/w/index.php?title=Larry_Kramer&oldid=1079940042)

what's going on right now. Specifically, the media coverage of AIDS in the United States really peaked and then started to decline. But, at the point that it was declining and kind of focusing on the rest of the world—that was the point that cases among Black Americans surpassed cases among white Americans in the U.S., right? So, there was this huge focus on AIDS in Africa and the Global AIDS crisis starting in the late 90s/early 2000s when we still had and continue to have an AIDS crisis right here in America but we're not putting our aid there. We're not putting... [inaudible]. So, I'm very concerned about the same thing happening with long COVID because I see this, again, a refusal to view it intersectionally. Refusal to—even the policies that we're seeing happen right now. This huge emphasis on vaccines when I know a lot of long COVID patients that weren't able to get a second dose or even a first dose of the vaccine because of the detrimental impact it had on their health, right? That's not to mention all of the economic barriers that exist to accessing vaccines and some of the cultural barriers in some communities that are preventing people from feeling safe going and getting vaccinated. So, [unclear] kind of see this get, and it's happening already, seeing this get siloed off as a problem of the poor, and the disabled, and the elderly, and the Black, and Brown, and that white upper middle-class people are going to be really encouraged to just forget about those people and continue living life and quote unquote, "getting back to normal." So, I think that that's something... you can't address the pandemic without addressing racial justice. You can't talk about long COVID without talking about medical racism and medical sexism and you can't talk about any of this without addressing the broken healthcare system and how difficult it is for... Right? It was difficult for me to access healthcare for this illness to some extent and in many ways, I had a lot of the privileges and safety nets that other people don't have. So, when we're talking about undocumented⁵² folks, and uninsured folks, and people who are coming from low-income families. Some of the people that I was talking to in that first group chat were living in multi-generational homes where many people in the home were essential workers, and so I just have a real concern that there's been a focus on science and public health policies as this singular, objective tool of science without really looking at how it intersects with these other larger movements and struggles. And I think the other movement that I am [unclear]... not talking about COVID within the context of is the climate justice movement. Because I've seen people say, "Oh COVID is distracting from that," and I feel like this is the first—well it's certainly not the first test—but this is one of the largest tests of how we are going to grapple with climate change and this massive rush to return to normal and kind of... The only people who need to sacrifice are the ones who have already sacrificed so much... that feels like a very clear parallel with what could go wrong with climate change, not to mention there is a direct correlation between increased disease and climate change

⁵² An immigrant is said to be "undocumented" when they do not have the legal right to remain in the United States or valid documents, such as an unexpired visa or work authorization. (Gasson, Kristina. "Who Is an Undocumented Immigrant?" Nolo. Accessed August 3, 2022. <https://www.nolo.com/legal-encyclopedia/who-is-undocumented-immigrant.html>)

and I think that's something very important as well. I had hopes at the beginning of the pandemic that everyone would change their approach to disability and become so much more intersectional in their approaches in general to COVID. I don't know that that's necessarily happening. I'm feeling a little depressed at this specific moment. I still have some level of hope and one thing that gives me hope is there are med students in my... you know, my age. I'm 28. I just turned 28. There are med students that I went to high school or college with who have been DMing me throughout the pandemic saying, "Thank you for teaching me about long COVID. I really care about this." One of my best friends is in medical school right now and they're very educated on long COVID and send me articles about it and that sort of thing. And so, there is this part of me that's like, "Maybe this next generation—if they can make it through this hellscape⁵³ that seems to be med school—but maybe this next generation of medical students who are a little bit more diverse despite all the barriers." You know, my friend is non-binary⁵⁴ and has immigrant parents, right? And another person I'm talking to is a feminist who also has immigrant parents and watched her own mother be mistreated in healthcare systems. So, I feel like maybe, maybe if there's a greater awareness on that end, some things will change. But I can't say I feel... super optimistic right now on December 27th, 2021 [laughs].

AD: No, I think that's a great point. I'm curious if you had the opportunity to be in front of a med school lecture or residents, what you might say to them? Like here are some key takeaways I'd like you to think about as you head into the field.

FL: Yeah, yeah. That's a great question. And one of the groups that Body Politic has been meeting regularly with is—I always get the acronym wrong—I think it's AAPM&R? The American Association of Physical Rehabilitationists and Medical Professionals or something.⁵⁵ Those are people further along in their career obviously, but I think the first thing I say to everyone in med school is like watch Jen Brea's documentary.⁵⁶ It's an amazing introduction to how post-viral and post-infectious illnesses have been neglected.

⁵³ A word to describe a harsh environment, similar to hell. ("Hellscape." *Merriam-Webster.com Dictionary*, Merriam-Webster. Accessed April 9, 2022. <https://www.merriam-webster.com/dictionary/hellscape>)

⁵⁴ Non-binary is a term commonly used by individuals whose gender identity does not fit into either of the binary categories of gender, i.e. man or woman. ("Understanding Non-Binary People: How to Be Respectful and Supportive." National Center for Transgender Equality. Accessed May 18, 2022. <https://transequality.org/issues/resources/understanding-non-binary-people-how-to-be-respectful-and-supportive>)

⁵⁵ Referring to the American Academy of Physical Medicine and Rehabilitation (AAPM&R), which focuses on supporting the medical specialty of physical medicine and rehabilitation (PM&R). ("Who We Are." American Academy of Physical Medicine and Rehabilitation. Accessed July 7, 2022. <https://www.aapmr.org/about-aapm-r/who-we-are-our-focus>)

⁵⁶ An American filmmaker that specializes in documentaries such as *Unrest*, and co-founder of the global network for ME patients, #MEAction. ("Jennifer Brea." Wikipedia. Accessed April 9, 2022. https://en.wikipedia.org/w/index.php?title=Jennifer_Brea&oldid=1062769446)

What it's like to be a patient with one of those illnesses, and the gender and racial dynamics at play. And I know they've also made some efforts to make that film available to medical schools and medical students. I think the other thing that has just become clear to me in the past year to two years to longer is the ways that fatphobia⁵⁷ and the capitalist focus on production really impact the medical advice that patients are given. So, even if we look at the changes that are going on right now with...

FL: Okay, we're back. [laughs]

AD: Yay!

FL: [laughs] sorry about that... But even if we look at like, the New York's governor just announced that essential workers only need to quarantine for five days—and this is not medical advice, right?—but it is being taken up by some of these health agencies—after testing positive even if they feel mild symptoms. There—I think throughout the pandemic—has been this question of, “What is the appropriate guidance for people?” And so much of it is based on this desire to remain productive and keep people productive as workers. And at the moment that they are not able to be productive in the workforce any more there's just this total abandonment. And so, I think that does bleed into medical advice to some extent. I mean something that we've seen throughout the emergence of long COVID is a lot of doctors trying to treat long COVID with aggressive exercise therapy as well as Cognitive Behavioral Therapy⁵⁸ in some cases. And I think just under—not every form of exercise therapy is inherently wrong or anything like that—but I think understanding a little bit more of those roots of fatphobia and this emphasis on productivity and actually digging a little bit deeper into the science of, “Well, is rest going to be more helpful for a patient? And does it, perhaps, not matter if the patient is 120lbs or 250lbs?” I think some of that is going to be needed right now. And I think that would be a really helpful place to start. And there's a lot of amazing people in healthcare also who are looking very specifically at the supposed correlation between weight and “obesity” and different health issues and trying to dig a little bit deeper into what is really going on there and how do we separate the science from what might be fatphobic cultural assumptions and that sort of a thing.

⁵⁷ Fatphobia refers to the discrimination and bias against people overweight individuals and the derogatory, misleading stigma around being fat or overweight. (“Fatphobia.” Boston Medical Center (BMC). Accessed August 3, 2022. <https://www.bmc.org/glossary-culture-transformation/fatphobia>)

⁵⁸ Cognitive Behavioral Therapy (CBT) is a type of psychological treatment based on different strategies to change thinking patterns and behavioral patterns in order to treat problems such as depression, anxiety, and eating disorders, among others. (“What is Cognitive Behavioral Therapy?” American Psychological Association. Accessed June 30, 2022. <https://www.apa.org/ptsd-guideline/patients-and-families/cognitive-behavioral>)

AD: I know you wrote a piece about resting your way to feeling better. And it seems like that's an important message to broadcast and probably one that can be difficult to both embrace and probably make possible given people's range of restrictions.

FL: Yeah, absolutely. And I think that's the other thing I hear from patients a lot. Like, "We want doctors that say, 'I don't know' when they don't know, and we also want doctors who recognize the limitations of the advice that they're giving." So, I had a thread—I mean I'm not a doctor and I try not to give medical advice [laughs] despite the many inquiries I get sometimes on Twitter—but I had a thread on Twitter the other day on some steps you can take if you test positive for COVID or if you think you have COVID to help you later on should you develop long COVID. One of the things I said was, "Listen to your body and rest if you can." You know, if you feel sleepy: sleep. If you feel like lying on the couch: lie on the couch. But I had to put the caveat of, "I recognize that all of this advice is incredibly limited in a world where there are not the necessary workplace protections in place to take this time off and people are taking care of kids." There are tons of limitations to getting enough sleep and accessing testing for the virus, which is one of the other things I had suggested, was to try to get that positive test early on, sometimes that can help with getting care. So, I think that's another thing. I know that a lot of people don't like going to the doctor because it feels like a report card, and you failed because you didn't jump through all of the ridiculous hoops that are not actually grounded in the reality of your life that the doctor suggested. So, I think as well that some of the best clinicians that I've talked to really recognize and work with what a patient's individual situation is and really remove shame and blame from the conversation as much as possible.

AD: It's interesting, because the field of work I did on Lyme disease⁵⁹ is now already ten years old. But, one of the most common responses that came up when I spent time with chronic Lyme patients when I would ask about what makes a good physician was, "We just want a doctor that says I don't know and is okay with uncertainty." And so that striking parallel and convergence, I think is really interesting. I think an interesting difference is the extent to which social media has been a part of knowledge production in a way that was not available in 2010 and 2011. I think that's a really... interesting contrast how much that has made... You know, just going through the various rungs of your ladder⁶⁰ from Twitter,

⁵⁹ Lyme disease is spread to humans through the bite of infected ticks and common symptoms include an expanding skin rash known as *erythema migrans*, as well as fever, headache, and fatigue. ("Lyme Disease." Centers for Disease Control and Prevention (CDC). Accessed June 30, 2022. <https://www.cdc.gov/lyme/index.html>)

⁶⁰ The expression "rung of the ladder" is typically used in reference to a level or a stage of a process. ("A rung on/of the ladder." Cambridge Dictionary. Accessed June 30, 2022. <https://dictionary.cambridge.org/us/dictionary/english/a-rung-on-of-the-ladder>)

Instagram—I can’t remember what the progression was—Instagram, WhatsApp, and then Slack. Those are things that even just a few years ago wouldn’t have had the same access. I think that’s a really interesting contrast and trying to map out spaces of legitimacy.

FL: Yeah. Yeah, definitely. And people with Lyme are another group that has been very much neglected by the medical system, and I think we’re learning from as well. But yeah, you’re absolutely right I think it’s a combination also of being a little later in time and the pandemic moving so many of us online for people that weren’t there before. But also, I have had a cellphone since I was like ten years old. My generation is just very tapped into this stuff, and so it didn’t feel super weird to me to be like organizing people via Twitter.

AD: Yeah, yeah, such an asset in that way. So, I thought maybe we might wrap up tying everything to feminism and contextualizing what you said up until this point with your thoughts about feminism. So, how you understand the term, “feminism,” what it’s meant to your work over the course of your journey, and whether you yourself consider yourself, a feminist?

FL: Yeah, I definitely consider myself a feminist, but I think my understanding of feminism and what it means to me has changed a lot. As I mentioned, I got a feminist education really, really young and quite early. And so, I was the sixth grader carrying the “feministing” tote bag and having everyone... You know, I grew up in the Aughts⁶¹ and the Bush years⁶² and it was not cool to be a feminist until I was like basically in college. And so, I think there was for a long time it was just sort of a way of saying “fuck you” to all the shit I didn’t like about the world. And it felt like a very... And I got a lot of shit for it also. But I think that a lot of my earlier ideas about feminism were about inclusion and representation. And I think a lot of that is just because I was socialized as a white girl and had a relative amount of privilege in terms of education and the sorts of opportunities that were provided to me. So, there was a real emphasis on like, we need to get girls like you into positions of power. Kind of that type of messaging, and then I think as I got older and especially the beginning of college through my college years just learning more, and learning about, how, perhaps, the systems themselves need to be rethought and it’s not just about getting an equal amount of women senators or women congresspeople or whatever it is. If the system itself is not serving the most marginalized, then it really can’t be called a feminist win. So, I think reading more

⁶¹ The “aughts” refers to the beginning of the 20th century, or the decade from 2000 through 2009. (“Aught.” Merriam-webster. Accessed July 7, 2022. <https://www.merriam-webster.com/dictionary/aught>)

⁶² George W. Bush served as president of the United States from 2001 to 2009. (“George W. Bush.” The White House. Accessed July 7, 2022. <https://www.whitehouse.gov/about-the-white-house/presidents/george-w-bush/>)

thinkers that... You know, I had Audre Lorde⁶³ books as a little kid, but I think getting to delve deeper into this idea of “no one is free until we’re all free” and understanding that. Also, I think a lot of changes happened in my own lifetime. Certainly, there are still major issues of pay disparities and basic issues between even the most privileged kind of woman and the most privileged man. But understanding a little bit more that for me, being a feminist is having that more intersectional approach and really focusing on: Who are the most marginalized populations, the voices that aren’t being heard? How can you amplify and center those voices? How can you not just continue to work within the same system but actually try to reinvent the system or reshape it if it’s not working for those who are most marginalized? And so, I think that’s been a major change for me as well. And then even just with my own identity coming to terms with... I’m genderqueer⁶⁴ and just understanding more about my own gender identity throughout life. I think that trans issues are a huge, huge part of the feminist struggle right now and I think that is absolutely an example of members of our community that are in many cases most marginalized... [unclear] reproductive rights for, you know, trans men and trans masculine people or whether we’re talking about sexual harassment and sexual violence and gender-based violence that’s happening, you know, to trans women on a very high level right now. And it’s been disheartening seeing some people who have called themselves feminists in the past pivoting away from those communities and trying to refocus the conversation only on cisgender women, so I see that as being a really important fight right now as well. I think it’s kind of transition from just absorbing a little bit more of what was “lean in”⁶⁵ type feminism and “she should run”⁶⁶ type feminism and moving a little bit beyond that especially after like I worked for a woman congressperson. I have campaigned... I campaigned for Hillary⁶⁷ when I was in middle school, but the world did not change overnight because of those things, and I also saw a lot of the limitations that those people were facing just because of the way they had chosen to try and effect change. And also

⁶³ A black and lesbian American writer, feminist, and civil rights activist against racism, sexism, classism, and homophobia. She was known for her poetry, prose, and her nonfiction works (“Audre Lorde”. Wikipedia. Accessed April 9, 2022. https://en.wikipedia.org/w/index.php?title=Audre_Lorde&oldid=1078209931)

⁶⁴ The term “genderqueer” is often adopted by individuals who do not conform to standard gender norms and may fluctuate between both binary genders, other genders, or none of them, falling under the “transgender” umbrella. (“What Does It Mean to Identify as Genderqueer?” Healthline. Accessed August 3, 2022. <https://www.healthline.com/health/transgender/genderqueer>)

⁶⁵ Referring to the book *Lean In: Women, Work, and the Will to Lead* by Sheryl Sandberg. Its success led to the creation of the nonprofit organization, LeanIn.org (“Lean In”. Wikipedia. Accessed April 9. https://en.wikipedia.org/w/index.php?title=Lean_In&oldid=1066661410)

⁶⁶ Referring to a nonprofit and non-partisan American organization that through data, education, and collective action, works to increase female participation in public office (“What We Do at She Should Run.” *She Should Run*. Accessed April 9, 2022. <https://www.sheshouldrun.org/what-we-do>)

⁶⁷ Hillary Clinton is a politician who served as secretary of state and New York senator, as well as First Lady to former president Bill Clinton. In 2016, she was the Democratic Party’s nominee in the presidential election, ultimately losing the election to Republican candidate Donald Trump. (“Hillary Rodham Clinton.” The White House. Accessed July 5, 2022. <https://www.whitehouse.gov/about-the-white-house/first-families/hillary-rodham-clinton/>)

partially because of who they were and some of the perhaps, bubbles that they existed in. So yeah. That's a big question, but I hope that...

AD: No, you answered it beautifully. And I was just thinking, I was just reading this morning your most recent piece on beauty pageants. And I'm curious about how some of those thoughts are informing your most recent work as of just two... I mean, I think it came out just a couple weeks ago.

FL: Yeah, that was really interesting, because I participated in that system in 2015 or something? So not that long ago, but there's a totally different approach amongst people participating right now. And I actually felt really heartened by the conversations that I had with a lot of the people that are participating in that system right now. Just even to see how much has changed in terms of—I mean obviously it's still not easy to be trans or non-binary and in many spaces it's not even easy to be gay, or lesbian, or queer, or pansexual—but just to see some of this greater level of comfort with expressing themselves authentically that they are even down to do it in one of the most traditional beauty pageants. And so, when I first starting research and writing about Miss America⁶⁸ the question for me was always like, “Does it matter?” and “Why does it matter today?” and that sort of thing. And I think this piece I approached with this different mindset of, “How is it serving these people?” and “How does it provide, kind of an outlet on—not just what like young, queer and trans people are interested in and how they're expressing themselves—but how are these traditional institutions going to grapple with a new generation that is not just going to put themselves into the cardboard cutout of what a Miss America is supposed to look like, or even, you know... Or whatever it is, what a journalist is supposed to look like or any of these different things... what an activist is supposed to look like and saying I'm not willing to compromise and sacrifice that part of myself. It was inspiring to me on a personal level just because I'm a people pleaser. I was like a “high achiever.” So, I have to even just in my personal life remind myself that I don't need to be the thing that makes people most comfortable. And I think that is a lot of what feminism is, right? Taking that question of—whether it's respectability politics or the comfort—like fitting yourself into what makes people most comfortable, when we say, “people most comfortable” we're generally talking

⁶⁸ Miss America is a competition between women that has historically been considered a beauty pageant, ranking contestants based on their physical appearance. Now, Miss America claims that the contestants are being judged solely for their talent and personal interviews. (“The Competition Evolves.” Miss America. Accessed July 7, 2022. <https://www.missamerica.org/competition/>)

about a patriarchal,⁶⁹ white supremacist culture,⁷⁰ right? A capitalist culture. So, we're talking about what's going to make the leaders of that culture most comfortable. And if we want to change that culture then we probably [unclear], you know, focused on that. Which is easy to say... The reality is that it could be dangerous to do that right now, but yeah, I'm definitely interested in that. And I think just going forward I'm really hoping in my work to continue exploring kind of the connections between all of these different things. You know that was also a pandemic story because it was a story of things that really changed during the pandemic when everything was thrown up in the air and people had a chance to actually question what really matters. And so, I think I'm really interested in just continuing to look at those intersections between how the world is changing both in regard to the larger culture and pop culture and media, but also how that relates to mass disabling events triggered by some of these, you know, climate change and that sort of thing and the expansion of even just... I keep thinking a lot about the number of disabled people has hugely expanded in the past year and a half and will continue to and what that's gonna mean, and... feels like somethings got to give but we'll see.

AD: Well, I'm so glad that you're thinking about those things, and I really look forward to where your work goes, and I look forward to reading it. And I guess before I end there's... nothing that you wanted to say that I didn't ask or anything else you wanted to add to our conversation.

FL: The only thing I'd say is I think I'm always like—when I'm thinking about feminism and even just social change and that sort of thing and my place in these movements is... We talked about this a little bit. I'm always kind of struggling with how much to both [unclear] that I know I can kind of have a proven track record with making change, right? So far example, another reason I stepped back from Body Politic was I don't have a background in advocacy. I have a background in solutions-based and advocacy-based journalism and community-building, but I'm not super experienced in interfacing with policy holder—policy makers—and trying to get them to change their policies. So, I think that's something that I'm always kind of thinking about and that I'm always just very wary of kind of the "savior-ist" narrative that can come into play in so many of these movements and one thing that's been really illuminating working with all of these different groups on kind of this patient led long COVID movement has been seeing that, unfortunately, in every movement

⁶⁹ The term "patriarchy" describes social relations of power that favors systemic gender oppression and gender inequality, thus enforcing dominance by the white, heterosexual male. ("Patriarchy and Power." Asian Pacific Institute on Gender-based Violence. Accessed July 7, 2022. <https://www.api-gbv.org/about-gbv/our-analysis/patriarchy-power/>)

⁷⁰ White supremacy is the belief that white, light-skinned people are superior to other racial groups, often associated with ultranationalist and fascist ideologies. ("White Supremacy." Britannica. Accessed July 7, 2022. <https://www.britannica.com/topic/white-supremacy>)

there also are those people who are gonna kind of swoop in and say—you know without the lived experience necessarily or with way more financial, economic... whatever privilege—and say, “Okay, I know the answer on this and everyone needs to listen to me,” and kind of drown out some of the smaller voices. So, I think I’m just thinking a lot about: How do you have a successful movement that doesn’t just have one spokesperson? And how do you also—groom is a weird word—but how do you train and expand spokespeople for a movement without just buying into what the media wants which might be racist and sexist and playing into some of these ableism⁷¹ and respectability politics. How do you use the media to get your message across, do what you want, and have an impact without allowing the media to define what the movement is if that makes sense?

AD: Mm-hmm. It makes a lot of sense and I think it’s a good challenge that... People will take some time to work on but I’m glad that you are. Well, this was such a pleasure.

FL: Thank you! Likewise.

AD: I’m so grateful for your time. And your willingness to share your story. It was really illuminating and inspiring so thanks a lot.

⁷¹ Ableism is the discrimination against people with disabilities, rooted in the misconception that disabled people are “inferior” due to their disability. (“Ableism 101: What it is, what it looks like, and what we can do to fix it.” Access Living. Accessed July 5, 2022. <https://www.accessliving.org/newsroom/blog/ableism-101/>)