

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

SITE: UNITED STATES

**Transcript of JD Davids
Interviewer: Abigail Dumes**

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JD Davids is a US-based health justice and communications strategist working with national networks of disabled and chronically ill people. He co-founded Strategies for High Impact and its Network for Long COVID Justice in 2021. Davids has been an external expert advisor to the NIH, CDC, and local health departments, and has served as a strategist and organizer with many pivotal groups, including ACT UP Philadelphia, AVAC, the Coalition for a National HIV/AIDS Strategy, Health GAP, the Health Not Prisons Collective, the HIV Prevention Justice Alliance, Positive Women's Network – USA and the U.S. Caucus of People Living with HIV. As a queer and trans person living with myalgic encephalomyelitis (ME/CFS), Long COVID and other complex chronic conditions, he writes and hosts conversations for The Cranky Queer Guide to Chronic Illness (@TheCrankyQueer), sits on the board of #MEAction and is a contributing member of the Patient-Led Research Collaborative, which released the first comprehensive study on Long COVID.

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. I'm a white woman with a white lace top. I have yellow, I mean, I guess I would call them gold and silver, circular earrings and brown hair, and a braid over my left shoulder. Over my left shoulder, I also have a framed piece of art with a red frame, and to my right are a set of bookshelves.

JD Davids: Hi! My name is JD Davids, and I am a white person with short brown hair wearing a headset that has a—an extension for the microphone that goes in front of my mouth with a fuzzy covering. And I'm wearing a brown t-shirt, and my background is blurred; it's an off-white color that represents the room I work in, in Brooklyn, New York.¹

AD: Thank you so much. And JD, thank you so much for being here and being willing to share your story with the Global Feminisms Project. I'm going to briefly introduce you, and then we'll move on to our questions. JD Davids is a US [United States]-based health justice and communications strategist working with national networks of disabled and chronically ill people. He co-founded Strategies for High Impact² and its network for Long COVID Justice³ in 2021. Davids has been an external expert adviser to the NIH⁴ [National Institutes of Health], CDC⁵ [Centers for Disease Control and Prevention], and local health departments, and has served as a strategist and organizer with many pivotal groups, including ACT UP⁶ Philadelphia [AIDS Coalition to Unleash Power], AVAC⁷ [AIDS Vaccine Advocacy Coalition], the Coalition for a

¹ Brooklyn is a borough of New York City, in the state of New York. It is in Kings County and ranks second amongst the most densely populated counties in the United States. It ranks as the most inhabited in all of New York City according to data from 2020. ("Brooklyn." Wikipedia. Accessed September 23, 2022.

<https://en.wikipedia.org/w/index.php?title=Brooklyn&oldid=1110201989>)

² Strategies for High Impact, also known as S4HI, is a resource group focusing on empowering the chronically ill and disabled people through organizational, coalition, and network support. They work to change narratives through communications, content creation, and campaigns. ("Our Strategy Circle." Long Covid Justice. Accessed September 24, 2022. <https://longcovidjustice.org/long-covid-justice/our-strategy-circle/>)

³ Long Covid Justice stems into 6 health equity groups led by people with Long Covid and similar conditions. It is managed by S4HI, and utilizes patient-led support groups and information sharing, research, grassroots community mobilization, and policy advocacy on the local, state, federal, and global levels regarding COVID-19 and the Long Covid pandemic. ("The Network for Long COVID Justice." Long Covid Justice. Accessed September 24, 2022. <https://longcovidjustice.org/>)

⁴ NIH stands for National Institutes of Health and is in the U.S. Department of Health and Human Services. It is the US medical research agency. ("WHO WE ARE." National Institutes of Health. Accessed September 24, 2022. <https://www.nih.gov/about-nih/who-we-are>)

⁵ CDC stands for the Center of Disease Control. It is one of the major operating systems of the Department of Health and Human services and works to save lives and protect people from health threats. ("CDC Organization." Centers for Disease and Control Prevention. Accessed September 24, 2022. https://www.cdc.gov/about/organization/cio.htm?CDC_AA_refVal=https%3A%2F%2Fwww.cdc.gov%2Fabout%2Forganization%2Findex.html)

⁶ ACT UP is a non-partisan organization that is focused on ending the AIDS crisis through direct action. It stands for the AIDS Coalition to Unleash Power. ("THE BASICS." ACT UP Philadelphia. Accessed September 24, 2022. <http://www.actupphilly.org/about-contact>)

⁷ AVAC stands for AIDS Vaccine Advocacy Coalition, and it was founded in 1995 to quicken the development of preventive HIV vaccines. Now, it has expanded its work in regards to HIV and global health equity. ("Our Story." AVAC. Accessed September 24, 2022. <https://www.avac.org/our-story>)

National HIV/AIDS Strategy⁸, Health Gap⁹, the Health Not Prisons Collective¹⁰, the HIV Prevention Justice Alliance¹¹, Positive Women's Network USA¹², and the US Caucus of People Living with HIV¹³ as a queer and transperson living with Myalgic Encephalomyelitis, or ME/CFS,¹⁴ Long COVID,¹⁵ and other complex chronic conditions. He writes and hosts conversations for The Cranky Queer¹⁶ Guide to Chronic Illness—the [Twitter](#) and Instagram handle for which is, [@thecrankyqueer](#),

⁸ This is the NHAS or Strategy, an organization created with the collaboration of ONAP, federal partners, and HIV community members. Their goals include preventing new HIV infections, improving health outcomes for current patients, reducing health inequities, and coordinating efforts to address the epidemic. ("National HIV/AIDS Strategy." The White House. Accessed September 29, 2022. <https://www.whitehouse.gov/wp-content/uploads/2021/11/National-HIV-AIDS-Strategy.pdf>)

⁹ Health GAP (Global Access Project) is an international organization dedicated to ensuring equal access to affordable health care and medicines for people with HIV. They focus on grassroots power and local community action, holding pharmaceutical corporations and governments accountable, and advocating for increased funding. ("Our Story." Health GAP. Accessed September 29, 2022. <https://healthgap.org/our-story/>)

¹⁰ This is a national initiative created in 2020 by CNP, the Positive Women's Network, [Sero Project](#), [TLC](#), and the HIV Caucus. They are involved with both gender and race issues pertaining to the US. They work to advance HIV decriminalization efforts through advocacy and litigation work, and for the decriminalization of sex work, drug use, and immigrants, with an end goal of ending massing incarceration in the USA. ("Who We Are." The Health Not Prisons Collective. Accessed September 29, 2022. <https://www.pwn-usa.org/issues/the-health-not-prisons-collective/>)

¹¹ This is a human rights network in the United States that was meant to deal with both social and policy issues regarding HIV/AIDS and for economic, social, and racial justice. However, this organization has been on a hiatus since 2018. ["HIV Prevention Justice Alliance (HIV PJA) Ends Its Services." POZ. Accessed October 1, 2022. <https://www.poz.com/article/hiv-prevention-justice-alliance-hiv-pja-ends-services>]

¹² This USA network is made up of women living with HIV. Their goal is to prepare and involve all women living with HIV in all levels of policy and decision making. They wish to inform and mobilize women with HIV and advocate for changes to improve their lives and rights. ("Who We Are and What We Do." Positive Women's Network. Accessed September 29, 2022. <https://www.pwn-usa.org/>)

¹³ This is a coalition founded in 2010 made to advocate for the representation and needs of people living with HIV in the USA (PLHVIV). They are run by the seven largest networks of PLHIV, representing 1.1 million people through their advocacy. ("Who we are." U.S. PLHIV CAUCUS. Accessed October 1, 2022. <https://www.hivcaucus.org/>)

¹⁴ ME/CFS stands for Myalgic encephalomyelitis/chronic fatigue syndrome and can cause problems with sleep, concentrating, dizziness and pain which heavily impacts daily function. It mainly occurs in people between 40 and 60 years old, happens to women more often, and has an unknown cause. 90% of those with it have not been diagnosed. ("What is ME/CFS?" Centers for Disease Control and Prevention. Accessed September 29, 2022. <https://www.cdc.gov/me-cfs/about/index.html>)

¹⁵ Long COVID, also known as Post-Covid Conditions, defines the long-term effects after an initial COVID-19 infection. It can include a vast range of continuous health problems and although possible in anyone, it is found more in people who suffered from severe COVID-19 symptoms. ("Long COVID." Centers for Disease Control and Prevention. Accessed September 29, 2022. <https://www.cdc.gov/coronavirus/2019-ncov/long-term-effects/index.html>)

¹⁶ This is a website dedicated to the self-help genre through journals, information, how-to lists and the like to overturn harmful norms and omission of consumer health info for those suffering from chronic illnesses. They have a variety of projects and events to inform and to advocate for justice for those with chronic health issues. ("Queer and trans people have always had to find new paths for our survival". The Cranky Queer. Accessed September 29, 2022. <https://crankyqueer.org/>)

all one word, sits on the board of #MEAction,¹⁷ and is a contributing member of the Patient-Led Research Collaborative,¹⁸ which released the first comprehensive study on Long COVID. JD, I thought we'd start by thinking about where you are today; how you would depict the journey that brought you to this point?

JDD: Thank you. Thanks for this opportunity, and all the work that your project is doing. Um—today I am—tired. It's been raining off and on, and that tends to trigger my fatigue. And also I've been feeling over the last couple months: tired in a sense of like feeling the years of my journey more than I do sometimes as a person living with complex chronic conditions, and also as someone who's spent a lot of my life centering HIV/AIDS activism. The monkeypox outbreak¹⁹ in the US, and the harm that is happening that doesn't need to be happening—that's happening through government neglect and misplaced priorities. Even amidst all the misplaced priorities and neglect that's happening with the—denial of the ongoing COVID and Long COVID pandemic. It feels very heavy, and is bringing me back to other eras of my life, where I feel incredibly grateful to have been a part of—um—feminist and queer-centering, world-changing organizing. And also I feel tired. And I feel the loss of dead comrades, who I would appreciate their wisdom at these times.

AD: Mm-hmm.

JDD: So I feel—Also I feel a very strange—I feel myself at the center of this very strange paradox, or irony, at a time of incredible suffering and mass disabling of Long COVID. The attention, insufficient as it is, but the attention so far that has gotten—has already resulted in—I've been able to access more effective treatments for my body, which holds a lot of labels of diagnoses that often are denied to others. But that are the—I've been able to get through—um—private insurance, white skin privilege, and access to specialists that many don't have. But haven't been able to have been on as effective treatments as I am now, that I've already been able to benefit through attention being put where it has not been put before, when there were already so many of us who have infection associated conditions. So it's a funny time. That's where I am today.

¹⁷ This is an international organization dedicated to helping those suffering from ME and those around them. They advocate for the education and recognition of its severity, and equitable care for those with the disease. ("Who We Are." #MEAction. Accessed October 1, 2022. <https://www.meaction.net/about/>)

¹⁸ The Patient Led Research Collaborative is a group of Long Covid patients who are researchers that founded this organization out of the Body Politic support group. Their mission is to facilitate patient-led research into the effects and to advocate for policies for those suffering from Long Covid with things such as access to care and representation. ("About the Patient Led Research Collaborative." Patient-Led Research Collaborative. Accessed October 1, 2022. <https://patientresearchcovid19.com/>)

¹⁹ Monkeypox is a disease that is of the same family of viruses as the virus that causes smallpox. Although the symptoms are similar, they are milder and very rarely fatal. In 2022, there was an international outbreak. ("What is Monkeypox?" Centers for Disease Control and Prevention. Accessed September 23, 2022. <https://www.cdc.gov/poxvirus/monkeypox/about/index.html#:~:text=What%20is%20Monkeypox%3F,and%20monkeypox%20is%20rarely%20fatal.>)

AD: So maybe we can—um—take it apart a little bit, and start with, sort of, where you see your advocacy journey again? And then we'll leave that up to, sort of, where your Long COVID journey began? And maybe tie those together?

JDD: Sure. When I was—I think second or second or third grade—my elementary school had a display in the hallway with, you know, construction paper that was about the winter holidays. And it talked about Christmas where it said, “We do this, we do that, and that talks about Hanukkah, and it said, “They do this, and they do that.” And I was one of a handful of Jewish kids in the school, and I guess I’ve always been attuned to matters of language and power. And I refused to be in the Christmas play. [laughs] So I think that’s one of my—yeah.

AD: Where it was born.

JDD: Yeah. So I—and another early memory was going to a day camp when I—earlier—when I was five or six years old. And having grown up in a very much majority white community, was in a day camp that included—lots of white kids and a pretty substantive number of African-American kids—and noticing how—I don't remember the specifics—but noticing tension around difference. And also how that changed my lens of viewing the community I went back to. So those are some of my early memories of thinking about that, as well as growing up mystified about gender, and not really feeling like I was doing it right. So my advocacy—um—beyond sort of individual acts of Christmas play resistance—started mostly when I was in college in the late eighties, and I joined the I was at Temple University,²⁰ and joined the Temple Coalition for Peace and Justice.

AD: Mm [nods head up and down].

JDD: And was learning. I was actually a Women's Studies major, which I have a degree in. And was trying to figure out how I could be, as an individual, a part of movement. And at the time there was the abortion—the Pennsylvania Abortion Control Act²¹ had passed, which was the first state level measure of that era that was cutting back on access to abortions. And I was interested in advocacy, and I went to some meetings on campus that groups came in to talk with us. And I felt like all they wanted for me was my money or my

²⁰ Temple University is a public university in Philadelphia, PA. It has prepared the grandest body of professionals in Pennsylvania state and is tied for 46th in the ranking of American public universities (“Temple University.” Wikipedia. Accessed September 23, 2022.

https://en.wikipedia.org/w/index.php?title=Temple_University&oldid=1111576364)

²¹ The Pennsylvania Abortion Control Act was originally passed in 1982. Women were henceforth forced to give 'informed consent' before having abortions and had a 24-hour waiting period upon getting the procedure to receive information about abortions. Additionally, it made minors needing abortions get informed consent from their parents, made wives inform the husband prior to the procedure, and required Pennsylvania abortion clinics to report themselves to the state. This act is tied to the famous case of Casey v. Planned Parenthood in 1992. (“Casey v. Planned Parenthood (1992).” Thirteen. Accessed September 23, 2022.

https://www.thirteen.org/wnet/supremecourt/rights/print/landmark_casey.html#:~:text=In%201982%2C%20Pennsylvania%20passed%20the,provided%20with%20information%20regarding%20abortions.)

vote. And I didn't have too much money, and you can't vote very often So I didn't really feel like there was much for me to do. And then a friend of mine, who had just graduated, introduced me to ACT UP, the HIV Activist group, and immediately—Well, it was very appealing to me, as someone who was starting to understand more about my own queerness that I hadn't understood before.

AD: Mm-hmm.

JDD: And where I late—a year or so later, when I started going to meetings, was immediately put to use, where everyone was asked. Sort of, “yo,²² what should be in this press release?” or “what do you think should be on the sign?” or “come to this meeting and help make signs.” And I really found a family and a community and a home there. And that's pretty much where I stayed for many years, and now have stayed also in terms of my—many of my values and practices come directly from my work with ACT UP Philadelphia. I was an active member for about thirteen years—

AD: Wow.

JDD: —and that really has formed much of who I still am today. So through the years then [chuckles]. I also—I always had some chronic health problems.

AD: Mm. That was going to be my next question.

JDD: Thankfully, not—Yeah, that's not um—severe. But I've also come to appreciate over the last couple of years how much those chronic health problems as a young person did affect my ability to participate in things; my relationship to school; my sense of self. And when I was in my mid-to-late twenties, I started having more chronic pain and chronic fatigue. And it was intermittent through the years, and many of our conditions are—many of our conditions—which are names or unnamed—can be intermittent.

AD: Mm-hmm.

JDD: And then, I—you know—I started working less hours, or working from home, or trying to adapt or deal. And then, when I was in my late thirties around when I was turning forty, I started having some pretty scary stuff as far as body-wide numbness and some other things that led to a diagnosis of Transverse Myelitis,²³ which is usually very acute inflammation in the spine that leads to rapid paralysis; that hasn't happened in my case. I've had it multiple times without as much severity, and more slowly. And that then led to a

²² A slang term used to greet others, get one's attention, display joy and excitement, etc. (“yo.” Dictionary.com. Accessed September 23, 2022. <https://www.dictionary.com/browse/yo>)

²³ This is a disease where inflammation on both sides of a section of the body's spinal cord interrupts messages that the spinal cord nerves send to the rest of the body. This can cause pain, muscle weakness, paralysis, sensory problems, or bladder, and bowel dysfunction. (“Overview.” Mayo Clinic. Accessed October 1, 2022. <https://www.mayoclinic.org/diseases-conditions/transverse-myelitis/symptoms-causes/syc-20354726>)

diagnosis of Multiple Sclerosis,²⁴ which was then changed later to a diagnosis as something more rare, which is called Neuromyelitis Optica Spectrum Disorder (NORD)²⁵—and then adding on Chronic fatigue syndrome (CFS).²⁶ I'm sorry—what was then called Chronic fatigue syndrome, but my diagnosis was for ME, Myalgic encephalomyelitis, or often shortened, to ME/CFS, and then Fibromyalgia.²⁷ And then I got COVID twice and have Long COVID. All of my chronic conditions—some of which can be quite severe—I have mild to moderate. And um—in many of them, you know—Long COVID—everything's sort of atypical 'cause so many things can be a part of it. But, many of the other conditions I have I'm—in some ways—atypical for them. So that's my situation [lightly chuckles] of atypicality. And I've also had atypically good access to care that's denied to many people.

AD: Mm-hmm. So you mentioned that you had COVID twice. Can you describe a little bit that timeline-- the first experience you had with COVID?

JDD: Yeah, sure. Well, I'm in New York. And I thought that I would get COVID rapidly, and I had a sense that I would be okay. And what came first for me was gathering online with other chronically ill and disabled people and our allies and realized that there wasn't anywhere for people to sort of talk about what was happening. And we were being talked about. As you know, everyone was going to be—everyone who counted was going to be okay, because this act—this was most dangerous for supposedly people with co-morbidities and old people who don't matter. And so we gathered, and I helped pull together a Webinar²⁸ on March 7th of 2020.

AD: Wow.

²⁴ This chronic central nervous system disease causes the body to attack itself by mistake. It is unpredictable with varying symptoms and there is no cure yet. Symptoms may include vision problems, trouble walking, paresthesia, etc. ("Multiple Sclerosis (MS)." John Hopkins Medicine. Accessed October 1, 2022.

<https://www.hopkinsmedicine.org/health/conditions-and-diseases/multiple-sclerosis-ms>)

²⁵ This disease, AKA Devic's disease, is chronic and affects the brain and spinal cord, where inflammation affects the nerves. It normally has the effect to cause vision problems and impaired mobility. ("Neuromyelitis Optica Spectrum Disorder." NORD. Accessed October 1, 2022. <https://rarediseases.org/rare-diseases/neuromyelitis-optica/>)

²⁶ Chronic Fatigue Syndrome is a disorder with no underlying medical condition cause that causes extreme long-lasting fatigue that affects daily function and does not improve with rest nor sleep. Effects include difficulty with memory, focus problems, extreme dizziness, and the inability to do much physical or mental activity. It is also known as ME or ME/CFS or in most recent times, SEID: Systemic Exertion Intolerance Disease. ("Chronic Fatigue Syndrome Overview". Mayo Clinic. Accessed October 1, 2022.

<https://www.mayoclinic.org/diseases-conditions/chronic-fatigue-syndrome/symptoms-causes/syc-20360490>)

²⁷ This is a musculoskeletal disease that causes pain, fatigue, and sleep, memory, and mood problems. It amplifies painful sensations from the brain and symptoms normally start with a triggering event such as infection, extreme stress or trauma, surgery etc. There is no cure, although there is prescribed medication and activities. ("Fibromyalgia Overview." Mayo Clinic. Accessed October 1, 2022.

<https://www.mayoclinic.org/diseases-conditions/fibromyalgia/symptoms-causes/syc-20354780>)

²⁸ A webinar is a presentation or seminar that is given virtually through the internet rather than in-person, allowing people from all over to hear the presentation, learn, and ask questions to the presenter ("webinar." Dictionary.com. Accessed September 23, 2022. <https://dictionary.com/browse/webinar>)

JDD: That was like—I think the first of its kind, which was about the coming pandemic in the United States, and considerations; the concerns and questions, and suggestions of chronically ill people.

AD: Mm-hmm.

JDD: And then on March, [long pause]. I'm sorry—yeah, March 16th, I felt really good. I didn't feel as sick as usual. On March 17th, I got a fever, and throughout my ten days of being symptomatic for COVID. I actually felt less ill in some of the aspects of my chronic conditions. Less chronic pain, less congestion, different kinds of fatigue, less of some, more of another. And then, as the fever subsided in the last couple of days, those came back. And then, I don't know if—if I had some aspects of Long COVID then. When a person has complex chronic conditions; there's a lot of ebb and flow. I know I didn't have severe Long COVID, that's for sure.

AD: Mm-hmm.

JDD: Um—the second time, though—I mean I felt like I probably had some sort of enhanced fatigue. I was having trouble with word finding and names, and it felt like I had some damage to my voice, harder to talk loud and things. The second time I got it—happened um—well, the order is—on February 23rd of 2021, I got the Moderna²⁹ shot. At 3 A.M. on February 25th, I passed out in my home and broke my ankle and the next day I spent about eight or nine hours in an emergency room—

AD: Oh my gosh.

JDD: —and needed surgery. So when I went for pre-surgery assessments the next week they found out I had COVID. So I either had it before the vaccine. I got it at the vaccine site, which was also doing testing—

AD: I see.

JDD: —in that kind of a small, not very ventilated place, or I got it in the ER, where there wasn't very good masking going on—good compared to today's standard.

AD: Mm-hmm.

²⁹ Moderna is a US-based public pharmaceutical and biotechnology company. It was founded in 2010 and is based in Cambridge, Massachusetts. The company mainly prioritizes mRNA vaccines, specializing in mRNA therapeutics. Their only commercial product as of now, is the COVID-19 vaccine (“Moderna.” Wikipedia. Accessed September 23, 2022

<https://en.wikipedia.org/w/index.php?title=Moderna&oldid=1107729164>)

JDD: So I got ankle surgery two days later. And again, I know I did not have severe COVID. I did not probably have moderate COVID. But, it was having just had surgery; it was confusing what my symptoms actually were.

AD: Right, I bet.

JDD: And yeah. After that I had more. It was more clear—I think I had Long COVID, as far as like—more—much more brain fog, more trouble with words, more reactions to food and other things as far as like a lot more problems with watery eyes and congestion, GI³⁰ (gastrointestinal) trouble, digestive trouble. A lot of things—much of which has been helped now thanks to learning about treatment for MCAS,³¹ or Mast cell activation syndrome from other people with Long COVID, I actually now have less brain fog, less fatigue, and less GI trouble than before COVID. Because these—this stuff was probably going on before for me and it was exacerbated by COVID. And even though I've had excellent care, no one has ever talked to me about MCAS. There's now much more to do, but more awareness of it, because it seems like a huge percentage of people with Long COVID have it.

AD: Wow!

JDD: But probably a lot of us with ME/CFS, and other conditions do too.

AD: So you've mentioned your excellent care—the privilege of having excellent care. Did you find that your experience with Long COVID was made easier, having those pathways already set, or—?

JDD: My experience with Long COVID was made easier by COVID-19 Long-Haulers, people with Long COVID. And I've been a part of Body Politic³² since the beginning, or almost the beginning. Because of already being involved in COVID. And then, before it was called Long COVID. But—

AD: Right.

³⁰ This is the digestive tract of the body that includes organs that food and liquid travel through when digested and exit the body as fecal matter. The organs in the tract are the mouth and throat, the esophagus, the stomach, the small and large intestines, the rectum and the anus. ("gastrointestinal tract." National Cancer Institute. Accessed October 1, 2022. <https://www.cancer.gov/publications/dictionaries/cancer-terms/def/gastrointestinal-tract>)

³¹ This is a disease that causes repeated severe allergy symptoms because the mast cells in the body accidentally release too many chemical agents. Symptoms can appear in the skin, GI tract, the heart, respiratory system and the neurological system. It usually develops in adulthood and has an unknown cause. ("Disease at a Glance." National Center For Advancing Translational Sciences. Accessed October 1, 2022. <https://rarediseases.info.nih.gov/diseases/12981/mast-cell-activation-syndrome>)

³² Originally a queer feminist wellness organization created in 2018, it is more known for its 2020 COVID-19 support group that virtually connected 1,000s from all across the globe. They advocate for those who have been marginalized in health and medicinal care and empower them as a community. ("Patient-Led Care Center Historically Informed." Body Politic. Accessed October 1, 2022. <https://www.wearebodypolitic.com/>)

JDD: —chronic COVID advocacy.

AD: Right.

JDD: And so I already—I know from my experience with being a HIV advocate, even though I don't have HIV, my friends and loved ones with HIV have always helped each other survive. Or helped each other die in ways that people wanted to die as much as possible when that was possible. And so I knew that peer support includes, you know, looking at the research. Um—figuring out medical options that it had information on how to navigate providers. All of that was going to be coming from the people who were affected themselves.

AD: Mm-hmm.

JDD: In the case of Long COVID, many of the people who are affected are health care workers. And you know, researchers, scientists are among—are also among those who are affected, because so many people are affected. So there was a lot of peer knowledge. There was a lot of specialist knowledge that's now met peer knowledge, and that's where I got the most help. And you know, I got the most—to be honest, you know—I got the most help in a way by not having severe Long COVID. I don't know—I know that there's very—there's very, very few ME specialists, and one of them is someone who I'd been able to see in the past, and she is now a lifeline for many people with Long COVID. So I wouldn't have had access to her, presumably, for severe Long COVID, if needed.

AD: What in the end were treatments that worked best for you?

JDD: Well, overall in the trajectory of my life with complex chronic conditions, I don't know what works best for me, because I'm very—I'm very humble, or [pauses briefly]. I'm very aware of how easy it is to mistake sort of cause and effect, you know?

AD: Mm. Mm-hmm.

JDD: And so—but in terms of my—my [sighs] sort of—[pauses]—And also I don't know of all these conditions I have that are named: I have one body and one life in this one lifetime, and it's all me. And I don't know that there's actually distinct conditions, so to speak. I think, and especially, you know, in the case of if you look at what happened. For example, there used to be a lot of things called Multiple sclerosis, and then as more tests were developed, things get separated out, you know, and distinctions get made. And you know—I don't know what is what. But what I know is, I seem to have an immune system that in some ways is overactive, and in some ways not active enough. I know that I tend to get a lot of run-of-the-mill³³ colds and viruses frequently, and it would take me longer to shake them. I got—when my kid was a toddler—I got a lot of those toddler conditions, you know,

³³ This is an expression that is used to characterize something as average, common, or not outstanding in rarity. (“run-of-the-mill.” Merriam-Webster. Accessed September 24, 2022. <https://www.merriam-webster.com/dictionary/run-of-the-mill>)

that adults don't usually get. And I know that what helps me feel better and function better has been trauma therapy—somatic therapy.³⁴ That's—helped me with trauma and um—and gender transition. When I started—as someone who, like lifelong, has identified as genderqueer,³⁵ I haven't always had the language, but you know—as a tomboy or genderqueer or trans, or whatever—there's many words I've used through the years.

AD: Mm-hmm.

JDD: But my decision after I gave birth to a child to then go on low dose testosterone was started because I had data at the time that-- I don't know what it led to in the research world. But it was about potentially that they found that for cisgender³⁶ women who had lower endogenous levels of testosterone had more flares in multiple sclerosis than those who had higher levels. And so looking at that, and then looking at how many autoimmune conditions are much more prevalent in quote unquote women. I started on a low dose of testosterone, and then decided to do a more sort of comprehensive, hormonal transition to stop cycling. And to adopt a hormonal mix that was more frequently seen in cisgender men. And I was psyched about some of the secondary sex, you know, presentation changes that came with that.

AD: Mm-hmm.

JDD: And I feel that those two things—when I talked to my neurologist, who was treating me for that NMO (Neuromyelitis optica)--that, you know, most dangerous, rare condition I had or have. And I said, “you know, I'm doing the gender—gender stuff.” And I did this, this—trauma somatic therapy. Really feels like it has really changed who I am, and I'm going to go off the immunosuppressive infusions I was getting. I was taking my Rituximab,³⁷ and actually this was years ago, but I—part of why I wanted to get off was because I was afraid there was going to be a pandemic.

AD: Wow.

³⁴ This is a therapy centered around connecting the mind and body through physical and psychotherapy. Examples may include yoga or meditation to help with hard emotions or sensations. (“Somatic Therapy.” Psychology Today. Accessed October 1, 2022. <https://www.psychologytoday.com/us/therapy-types/somatic-therapy>)

³⁵ This term refers to those who have androgynous gender identities, rather than male or female. (“genderqueer.” Merriam-Webster. Accessed October 1, 2022. <https://www.merriam-webster.com/dictionary/genderqueer>)

³⁶ A term to refer to people whose current gender identity coincides with the one they were designated at birth. (“cisgender.” Merriam-Webster. Accessed October 1, 2022. <https://www.merriam-webster.com/dictionary/cisgender>)

³⁷ Rituximab is a medication used to treat specific autoimmune diseases – such as chronic lymphocytic leukemia, non-Hodgkin lymphoma, and more – and cancer types. It is given by slow injection into the veins, in order to combat the antigen CD20 that is detected on B cells in the human body. (“Rituximab.” Wikipedia. Accessed September 24, 2022. <https://en.wikipedia.org/w/index.php?title=Special:CiteThisPage&page=Rituximab&id=1108269183&wpFormIdentifier=titleform>)

JDD: Yeah [laughs], and um, and he said, “Well, you know, you have mye—atypical disease, so I prefer you to stay on. But what I really think is, your guess is as good as mine.” And so um—so he didn't disagree. He didn't say those were therapeutic, but that it was—could be a good guess. So those have been helpful, and then, you know. Now I take a mix of—I always need to count—but it's at least I think twenty-five different treatments most daily.

AD: Wow.

JDD: There are many are over the counter, but many are not, and some come from—there's one from a compounding pharmacy. There's one from a different mail order pharmacy. My—uh—I take a hormone suppressor that's from a specialty pharmacy as well as taking testosterone, and over the counter stuff. So my day-to-day management of my relatively mild, but super life-changing chronic conditions is pretty consuming and hard.

ADD: Mm-hmm.

JDD: And So even in almost best case scenario, like mine. It's important for me to say, “it's really hard.” You know? In terms of—I'm always running out of something, and my partner has Type 1 Diabetes³⁸ and a seizure condition. Between the two of us—

AD: Wow.

JDD: —and also does gender confirming hormones. So it's—you know—we're always out of something, and it's—it's a strain. It's a lot, and it all could be a lot easier. And it's really clear that things sometimes are as difficult as they are, because it just makes another dollar or two here for some—some or another company to have it be just that much more complicated, or to get just that much more out of my insurance, or for my insurance to get that just that much more out of having to pay for things. So I don't remember what your question was, but that's my—

AD: No, this is great.

JDD: [laughs heartily]

AD: This was—It all answered the question about what has worked, and—

JDD: Oh, also another thing that has work that's been important to me is a—a twelve-step recovery—as a sort of a program of belief that's fairly, you know, agnostic. At least as practiced here, in Brooklyn, that I can opt in and out—that doesn't cost money.

³⁸ Type 1 Diabetes is a disease that causes the pancreas to not make little to no insulin, which makes blood sugar unable to get into cells and build up in bloodstream. It usually appears in children, teens, and young adults, and it cannot be prevented. (“What is Type 1 Diabetes?” Center for Disease Control and Prevention. Accessed September 24, 2022. <https://www.cdc.gov/diabetes/basics/what-is-type-1-diabetes.html>)

JDD: That is in a lot of ways to participate in it—for someone who, you know, has a lot on my plate. That's been also really um—life changing and affirming. And so my medical conditions are physical, and that's really important to say and recognize. And dealing with the physical, emotional, mental, spiritual, and political aspects of my conditions--these are some of the things that have helped as well as peer support, and being a part of social movements.

AD: Wow. One of the themes that seems to be emerging in the conversations that I've had is the importance of rest and pacing. Was that part of your daily regimen pre-Long COVID? Is it part of it now? How? Where does that fit into that range of self-care things that you do?

JDD: Well—after I broke my ankle I had to be in bed for pretty much three months.

AD: Wow!

JDD: And so that was the first time that I ever really rested like that. But still, the way I was resting was far less intense and intensive than people with, you know, moderate to severe or very severe ME or Long COVID. I did things like, I, you know, watched things on the Internet. I read books. I did crossword puzzles. I typed a lot, you know, and so I—you know, coming up through AIDS activism--you know, where the some of the stuff that people would say, is sort of like, "While you sleep, we'll fight AIDS." It was there—was this real feel of like people were not going to live. And while they were alive they were going to give all they had, and that was the ethos that was for all of us. Whether we were living with HIV or not.

AD: Interesting.

JDD: I feel like part of what kept me in and drew me to ACT UP was having been raised in an abusive, chaotic household. I was ready for—and sort of my—my um most familiar state was that of crisis. And so joining a movement that was really fueled by crisis and that of crisis pace—is something that I did for many years. And when I think about what was happening, you know, in the year—the months before I got most acutely ill years later, with Transverse myelitis, I can look at the pace now that I was going, and see how—how hard it was. I have never really methodically used pacing, and I have—I have a relationship with rest that is characterized by trauma responses-- that rest can feel dangerous. And so I am—for whatever reason—having mild to moderate atypical presentation of these conditions has allowed me to only reach a certain level of progression in a very like hectic, overworking life like I had up to the point of when I, you know, got the transverse myelitis. And then, over time I have learned more about resting and pacing. And now, years later [brief pause]—I neither work like I used to, nor do I want to.

AD: Mm-hmm. Mm-hmm.

JDD: I think my sense of resting and pacing; it tends to be more sort of intuitive than scheduled. Um, and I also—[long pause]. There are also times, though—It just happened a

couple of days ago. It's happening less frequently since I started the MCAS treatments. But, um—where I do have to suddenly go lay down, and I have to go to sleep. And I um [long pause], I have had very long stretches in my life where I have been able to not worry about working. Like living collectively with people and sharing expenses in an anarchist, collective house that meant, I didn't have to work much for money, you know, through much of my twenties. Like, I have often had these sort of like bursts of being—working a lot, and then bursts of having a lot of choice about the work I do. That, I think, is also a form of rest in my life that has to do with, you know, having sovereignty over one's own time and body. And so I—So that's my long way of saying, “No, I don't. I don't. I don't rest and pace, but I have a very restful life now.” And I have particularly over the last, you know, three years—and for the foreseeable future—I have a much smaller life. And I already had only, you know, gone out to a nightlife event once or twice a year for years before, you know? I don't—I don't really want or need those things too much, you know? So for many people, you know, who say, for example, that “they've recovered from Long COVID,” when you talk to them, they then say, “how careful their life is now. And how different it is from their life before Long COVID.” So really what they've done—is they've adapted to Long COVID. And that does make real changes. It may even eliminate some symptoms entirely, or some of the conditions that have been unmasked or added on by Long COVID. Um—And so that's my situation. You know—I know that—I'm pretty sure that, you know, if I add much more on—like, for example, when I started the Network for Long COVID justice—I did kind of work myself sick again. And I started having a lot of trouble eating food—like, and trouble sleeping. Like, a lot of it was coming back, and it showed me that I—I can't do it. Even though I was feeling much more healthier. I still take a lot of care, intending to stay—to stay that way.

AD: Mm-hmm.

JDD: Yeah.

AD: Really interesting. So you sort of mark the beginning of your Long COVID advocacy on March 7th, 2020.

JDD: Yeah.

AD: What was that? What's been that trajectory over the last two years?

JDD: Um! [sighs] Well, I—I started in—Well, in January of 2020, I launched the Cranky Queer Guide to Chronic Illness.

AD: Okay.

JDD: And that's something I'd talked about for a long time—of wanting to, sort of, document my path?

AD: Mm-hmm.

JDD: Where I've had this pretty incredible life of being like in this super queer liberation path, and—been involved in world-changing HIV activism, like helping to get treatment, HIV treatment, to tens of millions of people worldwide. And um—working with a lot of incredible people who are no longer here or who may be here, but—but haven't really—not many people have heard of them, or know about their incredible work. And as well as a lot of what I've learned about coping—living with complex chronic conditions.

AD: Mm-hmm.

JDD: And so I think there's—there's also a lot that we have to share, and we get um—I—my last job outside working for myself--before this, I worked for a digital health site. And I'd never done that before, and I learned a lot about how—the reasons that digital health information um—the site I work for notwithstanding, which is quite good. But, how it's—it's really almost completely shaped by profit motive. And because the US—you can have direct-to-patient pharmaceutical advertising. And how um—we're chopped up into these little boxes by diagnosis, or specialty, or lack of diagnosis. But when you get down to it, you know, for the vast majority of any of us with—with chr—chronic conditions, like, there's something wrong with our poop, or pooping, our digestion. We're struggling with sleep—um, or fatigue, or various aspects of that; we have to deal with decision making about what treatments to try. When to stop them; when to start them. Dealing with side effects, looking at drug interactions, what to do with all the barriers put in place that makes it hard to get this stuff. There's so many things that we have in common. And so I named it a concept called “illder.”³⁹ That we are illders. So we are—no matter our age—we have a wisdom from being disabled and chronically ill. And so I wanted to share illder wisdom, and hear, get illder wisdom from others, and had queer conversations about the sort of life and times of the—the activist movements I've been able to be a part of.

AD: Wow.

JDD: And so that was the spirit through which I then, you know, helped do that gathering online on March 7th and uh—move forward as the cranky queer. And then what happened, was I got pretty pulled in, pushed myself in, or fell in [laughs]—to Long COVID advocacy, because I'm in this fairly unique situation of having um—come up through, not just HIV activism, but, I've done a lot of research advocacy. Um, and I have—that there's a lot of HIV researchers who work on COVID, too. Like there's a lot of overlap, and—and there's all the health inequities that we had expected would happen that are really, you know, so true still in HIV, and that are really—um—appallingly evident in the ongoing COVID pandemic. And I have complex chronic conditions where I know what happens as far as people who get a virus and never get better, or get differently sick, or, you know, all these ways it can happen. So I ended up just being in conversation online with a lot of people with Long

³⁹ Illders are those of any age who have much personal knowledge about the hardships of living with chronic conditions and who turn these into self-knowledge, growth, and connection amongst others. This term is in relation to Cranky Queer and living with chronic illness. (“About the Cranky Queer Guide to Chronic Illness.” The Cranky Queer. Accessed October 1, 2022. <https://crankyqueer.org/the-cranky-queer-guide-to-chronic-illness>)

COVID, who were in these groups that, and that—It's funny, because I say, “people with Long COVID.” And I used to say, “people living with HIV.” Many people with Long COVID say, “COVID-19 Long Haulers,” or “Long Haulers,” and um—or “patients.” There's a lot, you know, I'm part of Patient Led Research Collaborative.

AD: Right.

JDD: People talk about Long COVID patient leadership, and patient advocacy. That doesn't quite roll as much off my tongue—in part, because I know from ME, the vast majority of people with ME, and the vast majority of people with Long COVID are not patients—and can't get care, and don't have a diagnosis. Or maybe don't even know—that they're sick. Because they are so—they already have co-morbidities. They already have a bunch of chronic conditions. There are—there are communities where diabetes, hypertension, um—different conditions are the norm. Because there's such a—um. There's a lot that—that is, in terms of how our society runs, that is disabling people. Particularly Black and Brown people, immigrant people—um, particularly trans women of color, other trans people—are put in harm's way to be made disabled, and then made to work at low wages despite disability, you know?

AD: Right.

JDD: So this was already here, and so—so the patient—I very much support patient advocacy and self-advocacy. But “The Denver Principles,”⁴⁰ which was written, I believe, in 1982 by people with AIDS that says—it starts off by saying, “We are not victims, and we're only occasionally patients. We are people living with AIDS.” So this was the origin of that nomenclature that has been so important in my um—my liberation work. Is that um—people were saying, “We're not patients.” And in fact, a recent—a big campaign right now—years, you know, generations later—among—led by people living with HIV, who I work with and support, is in the Federal—for the Federal Government—for the U.S. Government—to have indicators of how to evaluate how well the efforts to treat people with HIV are going, based on quality-of-life indicators. Because for over a decade now, decades now, it's been: “Are people virally suppressed?” Because if you're on effective HIV treatment, and the virus is suppressed in your body, you don't—can't transmit to others. So if that's the measure of how people are doing, it may leave out tremendous aspects of their life that are tremendously important regarding living with HIV, that have to do with stigma, isolation, precarity, food insecurity, loneliness—that don't get measured—interpersonal violence. And so particularly, you know, many women living with HIV have been fighting for this to say, “Don't just ask me about how my virus is doing; ask me how I am doing.” Right?

⁴⁰ These principles outline recommendations for people and patients with AIDS, and the rights for those with AIDS. They recommend not to stereotype, scapegoat or vilify patients, and recommend them to be involved in caucuses and forums, as well as inform their potential partners of their status. Lastly, they also explain the rights to full sexual and emotional lives, quality medical treatment, privacy, and lifelong dignity for patients. [“The Denver Principles {1983}.” The Denver Principles. Accessed October 1, 2022. https://data.unaids.org/pub/externaldocument/2007/gipa1983denverprinciples_en.pdf]

AD: Mm-hmm.

JDD: So that is something that I think, you know, as we go forward in advocacy—as for COVID-19 Long Haulers, you know, I think it's so important to understand that as—as the movement does—in the groups I'm working with—of that, you know: It's not just those who are able to say, "I have Long COVID." Because, being able to say, "I have Long COVID," is a privilege. And sometimes it's about race, class, private health insurance, family support. And in order to move forward to a health justice movement, a health equity movement—I believe we need to establish comprehensive care for all complex chronic conditions, regardless of a diagnosis or lack of diagnosis. Any person with fatigue deserves care and support for that fatigue, even if they think COVID isn't real, even if they are my political adversaries; they still have the human right to health, even though they would deny that to me as a trans person. I want them to get treatment for their fatigue. And I don't want them to have to say, "I have COVID," particularly if saying that is going to lead to um—violence in the home, loss of custody to your children. There's reasons why people can't say they—they have Long COVID. Um—it could mean risking your employment, which then means losing your home, and your home for your children. There's a lot involved with saying publicly, "I have Long COVID." Everyone can and should—but just with HIV—it's not for me to say who should or shouldn't disclose their HIV status.

AD: That's really interesting. Yeah.

JDD: Yeah. So to answer your question [laughs]: I started working with a bunch of these groups that come together, including I was already, or—I think it was, I think, right before the pandemic. I think I joined the board of #MEAction, which is a grassroots-based,⁴¹ ME (Myalgic encephalomyelitis) patient-led, or community-lead group. And I helped to—I didn't do research on the wonderful, initial research of Patient-Led Research Collaborative that confirmed and described Long COVID. You know, it was the first real comprehensive report in the world as far as I understand it. But I helped push to emphasize, "patient-led," as part of what this report was, and have been hanging out there ever since. And I've worked to introduce some of the leaders of Body Politic, the online support group that—that Patient-Led grew out of, and the leaders of Patient-Led Research Collaborative to leaders in HIV research advocacy both inside and outside of NIH, and sort of make those connections. And then—umm—I started—I had the privilege of getting to talk with, and hang out with, the two women who started, "Marked by COVID,"⁴² which is an organization started by a woman whose dad was killed by COVID, but killed by the politics that encouraged him to go out there and get COVID, and her partner. And so our groups, plus

⁴¹ By using grassroots to describe an organization, it refers to ones that use collective action from local communities in order to promote political or economic movements either on the local, regional, national, or global level ("Grassroots." Wikipedia. Accessed September 25, 2022. <https://en.wikipedia.org/w/index.php?title=Grassroots&oldid=1094836045>)

⁴² This is a fully volunteer grassroots nonprofit that advocates for COVID-19 pandemic justice, remembrance, and the promotion of pandemic prevention. Their core values include the 5 R's: response, recovery, restitution, resiliency, and recognition. ("May their memories by a revolution." Marked by Covid. Accessed October 1, 2022. <https://www.markedbycovid.com/>)

the—the wonderful super grassroots, COVID-19 Long Hauler Advocacy Project,⁴³ which was started by Karen Bishof, who's an indigenous single mom who got COVID during some of the training for her work as an EMT in Florida. So our groups-- I was just so [sighs]—um—moved by these groups. And also they looked familiar—in, um, how things get started. And they're all way underfunded, and people are working as volunteers in ways that could even jeopardize their own health, you know? And so I wanted to help. And I saw that—um—you know, some of the work I had been doing, and still am doing, is—I work as a strategist with—um—national networks of people living with HIV primarily. And helping to figure out organizational structures and working practices, and campaign priorities and uh—plans that help move these networks forward. And so I wanted to help bring that to the Long COVID groups, and I—as I was starting to do that—and I was like, “I really want to help these groups. They're overwhelmed. There's so much to do.” And then pretty soon I realized, “Oh, yeah, this means I'm going to get overwhelmed” [laughs heartily]. “Oops!”

AD: [laughs]

JDD: So I uh—Yeah. So I've been—I was able to volunteer a lot of my work over the past year because of a COVID-19 small business loan. And um—which was a privilege that was unequally distributed, you know, across the United States, and it wasn't—it's not a big amount of money. But I was able to continue to develop my group, which is Strategies for High Impact, which supports national networks, and also to some degree does international work and local work um—to support networks of disabled and chronically ill people. And so that's, um—what's helped us start the network for Long COVID Justice, which is anchored—which was co-founded by me and my comrade, Gabriel San Emeterio,⁴⁴ who is a queer—and um, gender non-conforming person who's a Mexican immigrant in New York, who's living with HIV and Myalgic encephalomyelitis, and other complex conditions. So we are working to support anything we can do to help groups be able to collaborate together, or find the way forward, and—we'll see. We'll see what we're able to do.

AD: Wow, and that was founded—when was that?

JDD: Well, we officially founded—founded Long COVID Justice, in the beginning of 2022. We started working on it a little in 2021. But Gabriel and I have been working together for—probably most of the pandemic at this point on some of the HIV projects.

⁴³ This is a non-profit organization founded in June of 2020 that prioritizes the advancing of Long Covid understanding and finding solutions and assistance to those with Long Covid and their families through advocacy, education, support, and research. (“HOME.” C-19LAP. Accessed October 1, 2022. <https://www.longhauler-advocacy.org/>)

⁴⁴ They are a queer activist who works through advocacy and grassroots organizations regarding policies and issues that affect the LGBT+ community, low-income college attendees, and patients with HIV. They are a host of podcast Rainbow Notes NYC and are a MSW candidate for the Silberman School of Social Work. “Gabriel San Emeterio – Bio.” Hunter College. Accessed October 1, 2022. <https://silbermanscsg.com/gabriel-san-emeterio/>)

AD: So you mentioned the familiarity of the landscape as you came into Long COVID work. I'm curious with your deep and inspiring history with HIV/AIDS; What was—what was similar there, and what has been different?

JDD: Yeah, that's a good question. I mean—[long sigh]. You know, I—by the time I started doing HIV advocacy/activist stuff, when I joined ACT UP it was like um—1991. So AIDS as a syndrome, or—had been known about since '81. So it was ten years in, right? And ACT UP started in New York in '87; started in Philadelphia and many other places in '88. And so for one, people started [pauses]—there was—before there was ACT UP, there was, you know, people with AIDS supporting one another, and people—particularly in the gay community. But also in communities of drug users, you know, helping each other, um—in daily life, you know, and the end of life. And um—but as far as like organized groups, you know, like that wasn't [pauses]—as early on. And so, that's one thing I think is important to recognize is just how very early on it is.

AD: Mm-hmm. Mm-hmm.

JDD: There's um—the familiarity is, is people coming together and figuring out what they need to do, and also people who had not before had to rely on a medical system or public support, having this eye opening⁴⁵ experience, or having this new experience of like, “Oh, this is awful, and it's been awful like this for some people all along.” So it's a transition that um—gives people an opportunity to re-examine their own sort of positionality in a—you know—patriarchal, racialized, capitalist, horror show [pauses].

AD: Mm-hmm. Mm-hmm.

JDD: So it's an opportunity for people to, um—meet at the place of [brief pause] principles and values—to try to understand what they can do to change things for everybody. And you know, the—the large scale of Long COVID; looking at the large scale of HIV: these are the kinds of things that do reveal, or should reveal—the drastic inequities and the essential—essentially the unsustainability and inoperability of profit-driven racist and gender discriminatory medicine, social programs, and government. So it's a moment, right? And I think there's a—you know, there's a—[brief pause]. I often turn to a speech that was um—delivered by a HIV activist named Vito Russo⁴⁶ several times. He was in ACT UP New York. I didn't know him, and I think the speeches were made maybe before I was involved. But it's called, “Why We Fight,”⁴⁷ and he talks about living with—living with AIDS is like a war that's only going on for those in the trenches. Um, you know, you look around, and

⁴⁵ Eye-opening is an expression that is used when something surprises someone or gives someone a new perspective. (“eye-opener.” Dictionary.com. Accessed September 25, 2022. <https://www.merriam-webster.com/dictionary/eye-opener>)

⁴⁶ Vito Russo was a gay rights activist, an author (“The Celluloid Closet”) and film historian. (“VITO RUSSO.” National Aids Memorial. Accessed October 1, 2022. <https://www.aidsmemorial.org/post/vito-russo>)

⁴⁷ This is a speech Vito Russo said at both New York in May of 1988 and in D.C. in October of 1988. This speech advocates for patients with AIDS/HIV, talks about personal stories regarding friends, and shines a light on harmful stereotypes on the HIV/AIDS community. (“Why We Fight.” ACT UP. Accessed October 1, 2022. <https://actupny.org/documents/whfight.html>)

another bomb has dropped, and you've lost more friends. But no—but people who aren't in the trenches don't know what's going on—I'm paraphrasing. Um—It's not—Because it's not happening to them. And earlier, he says, you know, “If I—” or earlier, he says, “if I—If I'm dying for anything, I'm dying because not enough rich, white, heterosexual men have AIDS for anyone to give a shit.” So I thought, “Oh, wow, COVID's going to get you, you know, affect everybody and including white, rich, heterosexual men, and things are going to change now because it's—it's widespread.” And then, it—it really hasn't. I mean what it's shown—it has shown, and more have seen, I believe, the need for everything to change. And it has shown the incredible power of the State, and that—that profit is going to trump everything, and that profit will demand fascism—if that's what's needed—in order to—for capital to keep on its trajectory, right? So that's what we're seeing now. So that's—that's different than my work in HIV, where I think—I think I—I'm not much of an optimist, but I think there was part of me that felt like the horrors of the AIDS epidemic, which continue in different ways to this day.

AD: Mm-hmm.

JDD: But the acute horrors of intense—intensely high death rates and unmitigated suffering would be different if people were affected differently, you know? Like when there was Legionnaire's disease,⁴⁸ you know—it happened at the same time that HIV was starting around, you know? And there was—everyone jumped on it and figured out what to do. And that didn't happen with all that was going on with HIV. You know, that kind of thing. Oh, now it's going to happen; that didn't happen.

AD: Right.

JDD: So I'm feeling a lot of-- a lot of despair, and I think also what I witnessed in—as a HIV negative from the—from the privileged position of being HIV negative. But amongst my comrades who were living with HIV and living with AIDS, particularly in the era before effective treatment was—people really felt that, being a part of advocacy was very helpful to their health. And people would—would be a part of advocacy, even as it became clear that they likely were not going to live a lot longer. And it helped people stay connected and be in a supportive community. And because people with Long COVID, basically, many of them have ME, and it's likely that ME is exacerbated when you first are—you know—it's first revealing itself, or you first sort of acquire it-- the language on, “how to describe it to me,” is still not clear—that deep rest actually could be the most important thing to avoid chronicity, and avoid progression, and the deep rest--the lack of it could harm people. I think that creates a real challenge in terms of a social movement where I—it's both a challenge and an opportunity. Because the reality is—we need to have liberatory movements that aren't endurance tests, and we need to have liberatory movements that are deeply infused with—suffused—I don't know the word—surrounded by—disability

⁴⁸ This disease is a type of pneumonia caused by bacteria found in freshwater environments that can make their way into water systems, where people breathe in the water droplets or accidentally swallow it. (“What is Legionnaires' disease?” Center for Disease Control and Prevention. Accessed September 24, 2022. <https://www.cdc.gov/legionella/index.html>)

justice. And because not—even if it wasn't the truth that disability justice, which says that, “All bodies are worthy, and all of us—um—contribute in ways, whether they're recognized by capital or not, that are valuable. All of us are deserving of circumstances to contribute in ways that—that are good for our bodies and our spirits.” You know, we extra need that for Long COVID, because we could—people could be cementing in place lifelong illness and disability. The other thing, though I think we—we need is more and more support for what it means to live with lifelong illness and disability. And as much support as possible for people to be as well as possible in any state of mind, body or spirit. And um, the—the biggest—the biggest challenge, I think, across the board for many people with Long COVID—and I should say I'm not speaking—I'm often not speaking of the most severe. Because it's a—it's a whole level of intensity that I can—can't speak for, or characterize, and that often gets sort of—um—left out when you're talking about, you know, severe or very severe ME or Long COVID. So I want to make clear I'm not doing that.

AD: Mm-hmm.

JDD: For those of us who have intermittent, or mild, or moderate presentations—like, the biggest challenge is income and life, and being able to provide for ourselves and our families to have a place to live, food to eat. And so—without—you know, I think the—the real—one of the real things we should be winning from this pandemic that we needed all along is universal, basic income. That's the treatment we need for so much of Long COVID, in addition to—in a way that would be truly inclusive of all people, regardless of race, location, gender, immigration status. But to have the basics of our life covered, so we have the option to rest. Without that, I fear that—we end up blaming people for their own um—recovery or lack of recovery. Like, it's seen as you've—“if you've gotten better it's because you've done the right things, and you're good. And if you're not getting better it's because, you know, you're—you're not doing self-care, and you're bad.” You know? And you've done something wrong. And I think we have a really—the importance of an accountable and principled Long COVID movement rooted in disability justice is huge as we look at what's going to unroll in the next couple of years. Because, what we're going to do—is there's probably going to be potentially for some people with Long COVID there will be biomarkers found that explain some aspects of Long COVID.

ADD: Right.

JDD: So those of us without biomarkers—and I say that as someone who lacks biomarkers for like my most major diagnosis—will be even, you know, sort of left out in the cold and disbelieved more.

AD: Mm-hmm. Mm-hmm.

JDD: And if there's some treatment, and some people either can't get it, or don't respond to it, or can't tolerate it, or can't fit it in. You know, then it will be our fault for not taking the treatment. There's going to be all kinds of divisions. Or, if you take the treatment, and you don't get better—because you already had existing co-morbidities and chronic illnesses—like, you're not deserving. Or, if you had, you know, if you have fatigue—because you have

ME, but you didn't have Long COVID—Are you going to get that treatment? Are you going to be on the indication when FDA⁴⁹ approves the treatment? Is your insurance going to have to pay for it? You know, there's so much that's going to go down now—that the best-case scenario of understanding Long COVID and finding treatment—is going to include a tremendous amount of problems.

AD: Mm-hmm.

JDD: So even the best-case scenario is—should be a huge—like, the idea of what will happen with the best-case scenario should be a huge call to everyone who can support Long COVID leadership and groups that isn't now. Which is to say, pretty much all funders—with a few exceptions. Pretty much all of government—with a few exceptions—should be supporting to build up the infrastructure of leadership of people with Long COVID embedded in their own communities um—that were most, you know, affected by COVID and Long COVID, that already have high rates of disability and chronic conditions. To be ready, you know? To be ready to ensure that if we have a best-case scenario that actually is good for people, all people with Long COVID, and to do everything we can to ensure that we do have that best-case scenario.

AD: Mm-hmm. Wow! So to sort of synthesize some of the really powerful things that you said: Would a hope for a vision be—not only, you mentioned earlier, you support care for anyone with fatigue—with or without a diagnosis; universal basic income; some sort of formation of sort of mutual aid health care networks to support folks, particularly in areas and communities most hit. Would there be anything else that you would add to that list?

JDD: Yeah, I think that to really center caring, and to really develop the caring economy is something we all need. And so I—I think that—thank you for synthesizing all that. That was very helpful to me [laughs].

AD: No, it was all you beautifully laid out. I'm just—

JDD: Yeah, yeah, we need it. We need it for all—this is what health care should be. Like, if you look at diabetes: is the greatest example of why there's no guarantee that things will go well at all for Long COVID. You know, what we need for diabetes is: there's—there's proven programs at the community level, for example, for Type 2 diabetes,⁵⁰ which I'm talking

⁴⁹ FDA stands for the Food and Drug Administration. They protect the health of the public by ensuring the safety of human and animal drugs, biological products, and medical devices. They also ensure the safety of the US's food supply, cosmetics, and commercial products ("What We Do." U.S. Food & Drug Administration. Accessed September 24, 2022. <https://www.fda.gov/about-fda/what-we-do>)

⁵⁰ This is an impairment in the way the body uses sugar as a fuel when cells respond poorly to insulin and take in less sugar. Although it is more common in older adults, the increase in the number of children with obesity has led to an increase in children as well. There is no cure, and exercise and weight management is recommended. ("Type 2 diabetes." Mayo Clinic. Accessed October 1, 2022. <https://www.mayoclinic.org/diseases-conditions/type-2-diabetes/symptoms-causes/syc-20351193#:~:text=Overview,circulatory%2C%20nervous%20and%20immune%20systems.>)

about now, which, by the way, there's rising rates of it—particularly in children, but also adults—as a consequence of COVID, right? So there's more Type 2 diabetes. And so low-cost community-led programs that are about cooking, about eating, about ingredients, and about understanding diabetes that—that help people get also medical care. But also just like sort of activities of daily life and support to care for one another, um, greatly reduces rates of diabetes, complications of amputations, of suffering, right? And so what we need for Long COVID; we need for diabetes, which people think is, you know, so well known. And so you know, and of course we need free insulin, you know? And so we have this very, incredibly effective treatment, called insulin,⁵¹ that people can't get, or have to ration or have to ration test strips. And when you, when you open the canister for the test strips, they fly all over the place because the manufacturers can't be bothered to spend a couple more cents to have them all in a strip, or something that just feeds into the machine automatically, because they can't be bothered to give up that—any, any ounce of profit. So we need to have community-based care, and I love the Doula⁵² model.

AD: Mm-hmm.

JDD: Doulas are people who help people with transitions. So community Doulas, who can help people with a new diagnosis, with an emergent—emergency, with a gender transition, with a community with a family crisis. Doula care of people who know your community, and care about you and your community, who can come and help wash the dishes, can help look after your kids so you can get that care you need, and they—you can be trusted with—you can—you can trust them with your kids. And to them, for people who need that, you know, all the time. You know, to have no shortage of um—in-home services and support, and to have these be good living wage jobs, where people get training, where people get Union⁵³ protections, where people have the rights that it takes to be able to do these incredibly vital jobs, and have their own health be protected. And then—um—to have—all this community care is networked through, you know, centers of excellence that are continuing to develop the science and treatment for common, um—co-travelers and chronic illness like fatigue, like digestion, like a—like what's going on with microbiomes and such, you know? And um, that that research is deeply accountable to and led with community participation and community participatory research. And then implementation science, which is the science that looks at what happens when you take this research out to the real world: Does it still work? What makes it work? What makes it not work? That also creates um—uh—paths of employment and promotion, education—for community folks to

⁵¹ This is a hormone that lowers the level of glucose in the blood. It helps it enter the body's cells where it can be used for energy or stored. In diabetes, the pancreas cannot make enough insulin, or the body can't respond well enough, causing the glucose (blood sugar) level to increase. ("Definition: Insulin." KidsHealth. Accessed October 1, 2022. <https://kidshealth.org/en/parents/insulin.html>)

⁵² Doulas are formally trained birth coaches or companions who give care before, during, or after the birth by giving information, advocacy, and offering physical and emotional support. ("Doula." Wikipedia. Accessed by September 24, 2022. <https://en.wikipedia.org/w/index.php?title=Doula&oldid=1104154675>)

⁵³ Labor unions are organizations formed in order to protect workers' interests regarding wages, benefits, and work conditions. ("labor union." Merriam-Webster. Accessed September 24, 2022. <https://www.merriam-webster.com/dictionary/labor%20union>)

become the primary investigators; to become the PhDs; to become the scientists running the show. So yeah. That's—that's basically the plan that I think should happen [laughs].

AD: I love it. It's really—it's really wonderful. I guess, as we think about wrapping up the one question I want to ask, and then I'll open it up for you to make sure we hit everything that you wanted to talk about is: you talked early on about your awareness of language and power, and how you have navigated—um—queer spaces? I wonder how you now understand the term, "feminism?" How that's changed for you over time? And whether you consider yourself a feminist?

JDD: Um—yeah. I consider myself a feminist. So that's the easy question. Um—and as a feminist, I believe in [brief pause]—unlimited gender equity. And that, "unlimited," by also—any preconceptions of what gender is, you know? And um— [pauses]. I feel like when I was, you know—when I was growing up, I grew up—I was born in—at the end of 1967. And so you know, the word "feminism" was around in the landscape, though I grew up in the—I was in high school in the 80's in a very deeply gender-discouraging time. And as someone who really did have to perform gender—sort of learn how to be a girl in ways that didn't feel very right for me. So I—I really did—I had—I didn't know there was any real alternative, you know? So I had to sort of work at it, and you know, working at that almost cost me my life as a teenager in terms of drug use and sexual risk-taking and um—and compounded by um—harms as someone who was abused by a female relative. You know—um, the—the gender complexity is very real. And so feminism, coming into an understanding of feminism, particularly—I had the incredible good fortune of um—of um—I went to college and went to an Introduction to the Women's Studies class that was co-taught by Sonia Sanchez,⁵⁴ who's a visionary Black poet and liberationist. And seeing my life be able to—to like re-understand my life—thanks to learning feminism. Um—in the—the years that I was either able to dive in in college like really saved my life. So I think I would say that feminism saved my life.

AD: Mm-hmm. Wow.

JDD: Yeah. So um—I don't know how I would define it now. Um—and I think that I—you know—I—I actually—you know I really like to understand more about like, "How we—What do we do to change, to disrupt dominant narratives? And what dominant narratives about feminism, you know, can be disrupted through language and through actions and through—you know." So it's not an area of inquiry I've been able to like live in for—for a long time. But um—It's something that's very important to me, and—and also seeing my child's generation. Now my child's almost thirteen, and seeing the—both the power of some gender freedoms that they have, and their peers have, but still the tremendous pressures that come from a gender binary. Um, it's—it's really intense, you know? And so I feel really eager to like learn in this new generation, you know, how I can be of support? And in pushing further, and—you know—also as a trans parent, you know, and with young

⁵⁴ Sonia is an integrationist, an author of poetry, playwright, and lecturer. Her work focuses on black art and jazz poetry. ("Sonia Sanchez." Poets.org. Accessed October 1, 2022. <https://poets.org/poet/sonia-sanchez>)

trans people in my life. You know—how do we do that? So I'm excited about feminism, though I don't know how I think about it as a term. I mean, I embrace it. Yeah.

AD: Mm. Mm-hmm. JD, is there anything that you wanted to mention?

JDD: Well, one thing I wanted to mention is about language and narrative and power that I've been working on, and that, I think, is, I mean one of the things that—I—**Oh, I'm sorry. I have to go answer the door.**

AD: Oh, no problem.

JDD: Okay, I'll be right back.

[timestamp from 1:08:00 to 1:09:07 that could probably be cut]

JDD: Um—So one thing we've been working on is, we have a—a statement called, “Pandemics are Chronic.” And one thing that—that [sighs] has been so vexing but so instructive is even amongst people who are-- some health equity advocates, and people deeply involved in social determinants of health, have talked about COVID in binary ways. And um—you know—when I first learned about what binaries were, as a young feminist—it really, really [pauses]—helped me understand the world a lot better that—that for whatever reason binaries may be a handy thing for human brains, or something encouraged socially and politically by those who benefit from them. But there's this binary of COVID—was people talked about—there was either: you—you got COVID and you either died or you got better, you know? And they weren't incorporating people who were advocating for vaccine equity, for example. Or talking about—um, the—the huge—um—disparities amongst COVID rates and fatalities in Black and Brown communities. And there was not much recognition of “COVID is chronic.” And um, you know, chronic conditions do sort of break apart a binary. And so we wanted to put out the “Pandemics are Chronic” statement as a pledge, for people to say that they will talk about the chronic aspects of COVID and all pandemics. Because now—and there's been discussions of pandemic preparedness: “What we need to do next time”—that didn't talk at all about chronic conditions that come from pandemics. And if you think about it, AIDS is—is like—Long HIV, you know? Or like ongoing HIV disease, you know? It's Long HIV. And pretty much, you know, it seems like probably maybe all viruses—if not all—can have a chronic component, some more than others. With polio, post-polio conditions can surface decades and decades later. We don't know if that may also happen with COVID. So the importance of understanding that pandemics are chronic is a feminist pursuit because it breaks apart the binary of like, sick/healthy, you know?

AD: Right.

JDD: Like alive/dead, right? Like—like there is living with chronic conditions. There is the chronic, ongoing need for care, you know? And to be able to move forward now, in this moment of the third year of COVID, and not talk about um—in every aspect of whether there's going to be a pandemic coming, or there's new pandemics, or looking at, you know. No one is asking like: “is monkey pox chronic?” Can there be chronic sequelae, or for people—maybe even most commonly—for those of us who have chronic conditions or disabilities, things that may be more transient in other people may have chronic impacts for us, you know?

AD: Mm-hmm. Mm-hmm.

JDD: They may, you know, make us our—our chronic conditions worse, or they may linger longer enough to put us in jeopardy from something else that comes down the pipe, you know? So “Pandemics are Chronic” says, “that there's an opportunity here to recognize what has not been recognized before. When we look at chronic Lyme,⁵⁵ you know, when we look at um ME, which is often associated with a viral infection or other conditions, that—you know—that aren't even necessarily named. But that—that chronicity itself, I think, is—in some ways, perhaps—a feminist concept, because it's about—it's about not oversimplifying. It's about looking at what happens to everybody in reality, not just in like fairyland stories, or like—um—stereotypical ways. And it's about a need for—that life is about care and caring for one another and ongoing care. And so you know, even if there wasn't Long COVID, we would have chronic impacts of COVID-19 in—in bereavement, in grief, in disruption of family structures, in the losses that have happened. That alone is chronic impacts. But we have probably about at least one in five people who have had COVID has some sort of Long COVID. So the ease with which even those who-- with whom I am generally politically allied, sort of, were not intrinsically talking about the chronic aspects of COVID—led us to, you know, put out the “Pandemics are Chronic” statement, which we hope people will still sign onto. But it also speaks to just how easy it can be to overlook things sometimes, especially—acute COVID is really bad. This pandemic has been very bad, but it's also chronic. So I wanted to make sure I said that.

AD: Thank you so much, and it feels like a really powerful way to come full circle and to end.

JDD: Yeah.

AD: I'm so grateful I had the opportunity to interview you. Thank you for the, for the honor of spending the last hour and a half with you. We're really thrilled to have your interview as part of our Global Feminisms Project, and I know we'll all benefit greatly from it. So thanks so much.

⁵⁵ Lyme disease is the most common disease transmitted by a vector in the United States. It transmits through infected tick bites and can be diagnosed from symptoms or a rash that appears in 70-80% of infected persons. (“Lyme Disease.” Centers for Disease Control and Prevention. Accessed September 24, 2022. <https://www.cdc.gov/lyme/index.html>)

JDD: Thank you. Thank you. It's been an honor to be a part of this, and to get to have help sort of connecting my own history with the important work that's happening today. And I would also encourage people to check out the US Positive Women's Network. It's a national network of women and people of trans experience living with HIV—as a great intersectional, powerful feminist group run by Black and Brown women with HIV and trans people. So check that out, too [chuckles].

AD: We will for sure. Thank you so much.

[there's a little to delete from the video after the transcript stops]