

## Getting Curious with Jonathan Van Ness & Dr. Celeste Watkins-Hayes

**JVN** [00:00:01] Welcome to "Getting Curious" and Happy New Year! I'm Jonathan Van Ness, and every week I sit down for a 40 minute conversation with a brilliant expert to learn all about something that makes me curious. On today's episode, I'm joined by Dr. Celeste Watkins-Hayes, where I ask her "Why does being a person of color affect the kind of medical treatment they receive"? Welcome to "Getting Curious", this is Jonathan Van Ness. I'm so excited to introduce our guest today, Dr. Celeste Watkins-Hayes. Who is, you're a, you, what are all your titles?

**CELESTE WATKINS-HAYES** [00:00:37] So professor of sociology and African-American Studies at Northwestern University and then I'm a faculty fellow at the Institute for Policy Research at Northwestern.

**JVN** [00:00:47] Now, we've heard of this fellow thing before, but just what does it mean to be a fe-, you got to, that means you got to audition for like the panel or something?

**CELESTE WATKINS-HAYES** [00:00:55] There is a little bit of an audition. It's a review process. So the Institute for Policy Research at Northwestern is our Center for Scholars who are interested in policy relevant research. So we're not just interested in publishing things that are going to stay on dusty shelves. We want to influence public debate and policy debate. So you basically audition or apply to become a fellow at the Institute for Policy Research. And it's really a wonderful collective of faculty who are interested in shaping the public conversation.

**JVN** [00:01:28] And Northwestern's basically like it's the smartest school and all of the midw-, it is. And it's like it's like the Ivy League of like Chicago schools. 'Cause isn't it in Chicago?

**CELESTE WATKINS-HAYES** [00:01:37] It's in Chicago, Evanston, Illinois. And it's an amazing place. I've been there my entire career. I started in 2002. It is a place of brilliant scholars and African-American studies and gender and women's studies and sociology and all of these different fields and disciplines. And we come together in this really collaborative environment to produce great scholarship and produce amazing, amazing students.

**JVN** [00:02:06] Love.

**CELESTE WATKINS-HAYES** [00:02:07] Yeah.

**JVN** [00:02:07] So for all of us who maybe, like sociology is the study of?

**CELESTE WATKINS-HAYES** [00:02:12] People, culture, systems, institutions, structures.

**JVN** [00:02:16] Oh yes.

**CELESTE WATKINS-HAYES** [00:02:16] So basically we're trying-.

**JVN** [00:02:18] Standby. Tell. Oh, she really wants us to put our face like on the mic hole.

**CELESTE WATKINS-HAYES** [00:02:23] Oh right, in the microphone. Ok, right there, like right there.

**JVN** [00:02:23] Yes, the really like it to-, broaching all of your boundaries. You know? Just like, just so fucking close.

**CELESTE WATKINS-HAYES** [00:02:31] Got it. Got it, got it.

**JVN** [00:02:32] So sociology is the study of what?

**CELESTE WATKINS-HAYES** [00:02:37] People, cultures, institutions and systems. So the nice thing about sociology is it's a discipline that helps you understand the world. So if you're interested in how do people get to where they get to in life? Why do institutions operate in the way that they do? How can we better understand schools and prisons and neighborhoods and larger social structures that shape our world like racism and homophobia and sexism? Sociology is the discipline where you can do that. And then I'm also an African-American-ist, which means I'm a scholar of African-American studies and we focus on all those issues but center blackness and black people throughout the diaspora in that conversation.

**JVN** [00:03:23] Diaspora means?

**CELESTE WATKINS-HAYES** [00:03:26] People dispersed all over the world. So when we think about the African diaspora, it's basically people of African descent, black people who are dispersed all over the globe. So we focus on, yes, black people in the United States. But we also look at black people in Europe. Black people in Africa. Black people in South America.

**JVN** [00:03:45] In South America.

**CELESTE WATKINS-HAYES** [00:03:46] Absolutely. To understand a common experience. And the different experiences around blackness and black people.

**JVN** [00:03:53] This is like kind of off subject, but it's on subject, but off a little tiny bit. It's like because one thing I didn't realize I learned about this when I interviewed this doctor of American history about, it was like, "What was it like to live in Philadelphia in 1775?" was the question. But one thing she was telling that I didn't know about was it like a lot of like Brazil and like Central America and had a lot of the same like slave trade situation that was going on in North America. And I was just. It made me wonder about like this, because during the Rio Olympics, like the way that certain, certain things were being spoken about and like all of their like political upheaval, since it feels like they have some of similar cultural pain bodies and scars of race.

**CELESTE WATKINS-HAYES** [00:04:30] Absolutely. Absolutely. Because Brazil was a major site of slavery. It has a huge number of black people living in the country. But, but people who don't largely have power. Right? And people who are marginalized in particular kinds of ways on the basis of skin color.

**JVN** [00:04:49] So sorry I don't want to have to say it again, what's wrong with happening?

**SOUND ENGINEER** [00:04:53] Thank you. I just wanted to tilt for you guys so it's a little bit.

**JVN** [00:04:56] We just like to get that audio so, so refined, honey. Thank you.

**CELESTE WATKINS-HAYES** [00:05:02] Oh sure! Good, good, good. Thank you for getting us together.

**JVN** [00:05:03] Thank you. Sorry. So sorry. So sorry.

**CELESTE WATKINS-HAYES** [00:05:05] It's OK, it's OK.

**JVN** [00:05:06] Because you're everything you're saying is just like liquid gold just pouring out of your mouth.

**CELESTE WATKINS-HAYES** [00:05:11] Oh, thank you.

**JVN** [00:05:11] Yeah. So Brazil is also?

**CELESTE WATKINS-HAYES** [00:05:13] Yeah. Brazil was also the home of slavery. And, you know, as the slave ships moved, they didn't just stop in the United States. They stopped in the Caribbean. They stopped in South America. So you ended up with black people all over North and South America and the Caribbean. So part of what we're interested in understanding is how do people get racialized in a way that we have decided that we are going to organize people on the basis of the color of their skin. And we're going to distribute resources and opportunity on the basis of all things skin color.

**JVN** [00:05:46] Break that down.

**CELESTE WATKINS-HAYES** [00:05:47] How does that happen?

**JVN** [00:05:48] How did it happen?

**CELESTE WATKINS-HAYES** [00:05:49] Right. So when we think about racialized processes, we've got to understand that it's often tied to money. Right? So it's often tied to the need for cheap labor and it's tied to the need for people with capital to build more capital through cheap labor. So you've got to find a supply of people who can work cheaply or can work for nothing. And essentially, that's how we ended up with slavery. It was an economic system that was about fueling countries and the economic systems of countries in ways that stratified people and created these very brutal systems of control and domination because guess what, people don't want to work for free. Right? So how do you control people? You take away their families, you take away their access to resources, you take away their access to education, and you essentially subjugate them so that they are in a situation where they're working for free and they're highly oppressed. So part of what African-American studies is thinking about is, so what did that mean and what does that mean in 2019? But it's also looking at how did people resist? How did people rebel? Because in that story, it's a story of agency, right? It's a story of even in our most desperate and marginalized moments, people still can operate agency. And it may be limited agency. They may not have much power. But even within limited agency, there's there are things that can be done. So out of black culture, you get music, you get arts, you get politics, you get social movements, you get religion, you get all of these ways in which black people were determined to create their own destinies. And that's

what African-American studies tries to capture both the pain of the experience, but also the joy and the power and the politics of the experience.

**JVN** [00:07:51] Which, you know, if, if life being like, you know, really beautiful and also really tragic at the same time is like, what makes life beautiful then like, what a beautiful story. You know, I mean, it's so fucked up for all the parts of it that are fucked up, but also like the agency and the resourcefulness and the drive to be, to like learn and do everything that you want to do, like no matter the circumstances you're in is like really a story like such human perseverance.

**CELESTE WATKINS-HAYES** [00:08:15] Yes. And there in resilience. I think it was Ta-Nehisi Coates who calls it the ble-, the beautiful struggle. I could have that wrong, but I love that idea of the beautiful struggle. And, you know, no, if we had it, to do over again or through our choice, we wouldn't have this particular struggle but through it. Look what we've been able to achieve. And look how powerful this community is all over the world.

**JVN** [00:08:40] So, yes.

**CELESTE WATKINS-HAYES** [00:08:41] Yeah.

**JVN** [00:08:41] So in studying like sociology and African, African-American studies? Or just-?

**CELESTE WATKINS-HAYES** [00:08:47] Yeah. African-American studies.

**JVN** [00:08:48] African-American studies, I would guess you probably had to learn a lot about like history.

**CELESTE WATKINS-HAYES** [00:08:53] Oh, definitely. Yes.

**JVN** [00:08:54] So when did people start to be like, "You know, I think the slavery thing is kind of wrong, like we shouldn't be doing this like". Because I learned in that one episode of "What was like to live in Philly in 1775", the first abolitionist in Philadelphia was like around 1775. But like when was like, did we learn about that, like in England? Like when did other people get it together?

**CELESTE WATKINS-HAYES** [00:09:15] Well, it took a while. And, you know, arguably there's still people who question whether slavery was a bad thing unfortunately. We find ourselves having that conversation in 2019. There's these, you know, kind of debates that pop up. But-

**JVN** [00:09:29] What does that mean?

**CELESTE WATKINS-HAYES** [00:09:30] That basically or you know, when you think about the debates over, you know, Confederate monuments, part of that debate is how do we remember history and how do we remember the tragedy of history? And how do you remember the struggle of people who died for a particular culture, in this case, southern culture to persist. Right? And people who are brutalized through that. So maybe people don't necessarily want to see a flag or a monument that celebrates that culture in a particular kind of way, that kind of supre-, white supremacist culture. So one of the things that I think, you know, is really interesting to note is the way in which from the earliest days in which we were dealing with transatlantic slavery and seeing

the brutality, there were people, small in number, but there were people who were writing about it and resisting it. And there were actually black people as well who were writing about it. You think about Frederick Douglass when you think about Harriet Tubman, when you think about Sojourner Truth, when you think about Anna Julia Cooper, there were, you know, people who were writing about the brutality of racialized systems and our insistence on dividing ourselves on the basis of race.

**JVN** [00:10:48] And in the South during slavery, wasn't it like illegal to, like wasn't like learning to write and read like a form of resistance?

**CELESTE WATKINS-HAYES** [00:10:55] Absolutely. That was a form of resistance. And it was illegal. So you can imagine or would have the question, why would that be illegal? What's the issue with reading or writing? Well, we know that through education is freedom. Right? You get to read about other experiences, you get knowledge. You're able to traverse the world using a different set of skills, able to sell a different set of skills. So the fear was that slaves would be able to read and write. Be able to communicate with each other. Be able to organize resistance. Right? Through reading and writing. So that had to stop. So what's so interesting and you see this, you know, throughout history are the ways in which slaves found very creative ways to nevertheless communicate, whether it was through spirituals and music. When you think about something like the song "Wade in the Water", that's a song about how do you escape. Right? When you think about folktales, they get passed down from generation to generation. There were directions in there and instructions in there in terms of how to get to freedom, how to escape, how to rebel, how to resist. But nevertheless, you know, there was always this pushback against allowing slaves to get any kind of skills that would get them closer to freedom.

**JVN** [00:12:12] So you take slavery and then slavery turned into Jim Crow, which turned into like so many of the scars of the Jim, of Jim Crow era and white supremacy and racism, like it's all on our society now. But I do think that there is like a large point of people who like I remember being like a little kid being like 6 or 7 and learning about slavery in the middle of America. And back then people being like, yeah, that was 300 years ago. You know, what about it now? I remember like white people having that mentality about it back then and me being a child back then. I didn't really understand like how that was, should move so many hairs on my head. As I've grown up. I am very. I read Eckhart's Tolle, I know about about cultural pain bodies. I know about privilege. I know about how the ways that this does enable people who are white people to get ahead faster. It's like that whole thing of like that video, where it's like demonstrating privilege, where like where people certain people have a head-start where it's like, "Take a step forward. If your parents are married, take a step forward if you had help with your education". And it's like that. I don't know if you've seen that video, but you should Google what I just said and I'll explain to you privilege.

**CELESTE WATKINS-HAYES** [00:13:16] Yeah, yeah.

**JVN** [00:13:17] But it's like to the people that, you know, would say or it's like "I don't understand how those things affect us now", but they do.

**CELESTE WATKINS-HAYES** [00:13:24] Right.

**JVN** [00:13:25] And so from a doctor who studies that. What? I mean, you've written two books about how HIV AIDS affects, about how the, how HIV AIDS affects us now.

**CELESTE WATKINS-HAYES** [00:13:35] Right.

**JVN** [00:13:35] And the whole journey that it's taken.

**CELESTE WATKINS-HAYES** [00:13:37] Yeah.

**JVN** [00:13:38] And that seems to me that. I mean, it's like how do you connect those dots? But it seems pretty clear in my head how you connect those dots. But can you just through your studies and everything that you know, like connect those dots for us?

**CELESTE WATKINS-HAYES** [00:13:48] Sure. So post-slavery, we had a system, we had a very short reconstruct-, a period of reconstruction where black people had the right to vote and had rights to economic freedom and were able to build businesses. And that was a very, very short window in the late 1800s. So from about, let's see, 1865 to about, you know, 1874 and what closed in that door is Jim Crow and the realization that the entire racial order could be upended if black people had access. Access to voting, access to economics, access to neighborhoods, access to everything that had been, you know, kind of the spoils of capitalism. So there had to be a way to kind of keep the social order in the absence of slavery. And here we have Jim Crow. So you started to see segregation in terms of black people can live here, but they can't live here. They can work here but not work here. But it was also a lot of social conventions around you can't look a white person in the eye. You know, you can't go into a certain side of town or, you know, you would get hurt. And, you know, we also know that that was a period of racial terror through lynching. Right?

**JVN** [00:15:07] Yeah.

**CELESTE WATKINS-HAYES** [00:15:07] So part of what we see throughout much of the 20th century, right up until the Civil Rights Movement is this very clear legal, but also kind of social and cultural system that is really built to keep one group on top and another group on the bottom. Right? So the idea that when the HIV epidemic comes along all the way in the night-, in 1981, where it gets discovered, we're still grappling with those systems. In 1981. We're still grappling with residentially segregated neighborhoods, for example. So while it is illegal to discriminate on the basis of race, when people are selling or renting houses, people still do it all the time. Just look at our neighborhoods and how segregated they are. When you think about access to educational opportunities, people of color are the least likely to get access to the very, very best educational opportunities. That's changing, but not changing fast enough. So. And then when you think about health care, right? So who gets access to health care? Who gets access to the best doctors? Who gets access to the best information about their health? We often find that people of color are in a disadvantage position. So when the HIV epidemic hits there, already these kind of structures of marginalization, that leaves certain communities super vulnerable to protect themselves against an infectious disease. Because we think about how does an infectious disease get spread, it gets spread from person to person. What prevents it? Well, number one, it's information, right? It's maybe a medical inform-, intervention, but it's also people having the freedom to live their lives with limited constraints. Right? So if you're worried about food on the table, maybe you're not always going to use condoms with the boyfriend who's paying the rent, but you're not quite sure if he's been tested, if he's living with HIV-.

**JVN** [00:17:09] And you're not going to ask if he's the one who's like-.

**CELESTE WATKINS-HAYES** [00:17:10] And you're not going to ask if he's the one paying the bills. If you're in an environment where the local health care, care clinic has a three hour wait in the waiting room. And you've got a job that if you're late, you could easily be fired. Maybe you don't go to that doctor's appointment if you know, I don't know if I'm going to be there for an hour or I don't know if I'm going to be there for four hours. But I know I got to get to work on time. So maybe I'm not going to do that doctor's appointment. Maybe I'm not going to get tested. Maybe I'm not going to get, go get information about HIV. So what you see when the epidemic hits are all these vulnerable communities. In terms of GLBT communities who have a difficult relationship, too, with the health care system, who are subject to all kinds of questions around their sex lives and their sexuality. You have vulnerable black communities who are dealing with the legacy of slavery. You have brown communities who are dealing with the legacy of Jim Crow that they also had to deal with. You have women who are not necessarily in power to talk about their own sexual health. So what HIV does is it finds all of those pockets of vulnerability within a society and it exploits those pockets of vulnerability. So that's why the epidemic looks the way that it does. HIV could happen to anybody, right? Anybody could acquire the H-, could acquire HIV. But we know that it disproportionately affects people who are living within a context of vulnerability.

**JVN** [00:18:43] So we're going to be right back with more Celeste Watkins-Hayes after the break. Welcome back to "Getting Curious". This is Jonathan Van Ness. So, and Dr. Celeste Watkins-Hayes. So basically, so ok, time travel story. So 1865, the Civil War ends, I think. 1861 to '65. Then there's like ten years of like reconstruction. And then the Jim Crow laws were enacted like some time like '75 also too did not prep Dr. Celeste Watkins-Hayes for this, for this particular question. So we're really just getting through this together. But basically it's like. So that's like about ten years. And then we're those Jim Crow like segregation laws, were those like confined to the South or did you find them like in California, for instance, or like was there other places where there was like Jim Crow? Like, was it like all over the U.S.?

**CELESTE WATKINS-HAYES** [00:19:37] You know, and that's a myth that it was, that the South was the only place that had slavery and had Jim Crow. And then North was so awesome. No, there was slavery in the North. No, there was Jim Crow in the North. No, there was Jim Crow in the west. You know, throughout the United States, there have been these systems of racialization and racial inequality and segregation in terms of access to neighborhoods, education, jobs and healthcare, and disproportionate use of the criminal justice system against people of color to contain and control. So that has been happening all over the country. But the north was perceived as a more free place because it wasn't always so in your face. They overturned some of the laws sooner. And there was, you know, a way in which people could kind of economically make away for themselves in the north that they didn't necessarily have the opportunity to sometimes in the south. So that's, I think, how the north got viewed as like this promise land of its still going to be segregated, but at least we have a shot. Right? And I think that's what moved a lot of people.

**JVN** [00:20:50] So the thought of Jim Crow being only South is just not true.

**CELESTE WATKINS-HAYES** [00:20:52] That's not true. Yeah.

**JVN** [00:20:53] Which I think is important for us all to remember.

**CELESTE WATKINS-HAYES** [00:20:55] Yeah.

**JVN** [00:20:55] Because I think so many people in the north, especially white people that live in the north now feel like a little like "Well, that never happened here". But really this ugly, this, this ugly history of slavery has been pervasive all over the U.S.

**CELESTE WATKINS-HAYES** [00:21:06] Absolutely. The North had a shorter history of legal Jim Crow, but certainly a long, a shorter history of legal Jim Crow. But certainly a long history of informal kind of de facto Jim Crow.

**JVN** [00:21:22] And when you talk about I think one thing I learned about a lot about from "The 13th" and from Ava DuVernay for that just incredible documentary was about how like in a lot of states, if you get charged with a felony, like your voting rights are taken away. And so when we talk about like voter suppression and how and especially where like drugs and voter suppression goes hand in hand and like we literally have President Nixon on tape from Watergate saying that like, oh, let's make marijuana a schedule, a one offense, so that that way all of the hippies and literally black people, because that's the majority, because like they couldn't make cocaine a Schedule 1 offense, because then that would make all these white, blue or like, you know, Republican voting people, felons. So they're like, how can we isolate it to being more like LGBTQ people or hippies, as he called it, and then black people? So like, oh, we'll make marijuana a schedule, one offense and we'll make crack a schedule 1 offense. But cocaine, we'll make a Schedule 2 offense so that that won't you know, that's literally on tape like that is in our president's on tape saying that. So that was like early 70s, which was like eight, nine years before like HIV AIDS hit. So the only reason I'm saying that is, is because when you talk about these systems of marginalization and oppression were already set up and were very well oiled in place, all these things were really coming together.

**CELESTE WATKINS-HAYES** [00:22:33] Right. When we discovered the epidemic.

**JVN** [00:22:34] Right.

**CELESTE WATKINS-HAYES** [00:22:35] Absolutely. Absolutely. And, and that's why it's so important for us to talk about HIV as an epidemic of inequality. Right? So we often focus on HIV as an epidemic of behavior. Right? So it's about how many people did you have sex with and are you using I.V. drugs and what are you doing? What are you doing? And, you know, kind of trying to focus on it as an individual situation.

**JVN** [00:23:00] You should have done better. You should have thought better. Yeah.

**CELESTE WATKINS-HAYES** [00:23:02] Right, right. And there's no question that people can do things to be safe and protect themselves. We're not saying that, but what we're saying is the likelihood of transmission is higher if you're in a context of vulnerability. If your community, if your family, if your neighborhood is in a context of economic and social and medical vulnerability.

**JVN** [00:23:25] That's a really big words because it's like, and so the other thing, though, is that if you are a, 'cause if you're a white queer person, it's not, you're not, you, cause like for me, I was able to go to a Planned Parenthood. I got, I found out that I had HIV. I was able to get the treatment that I needed and as a white queer person that had it's own issues. But if you're a black queer person or a Latino queer person or a woman queer person, like those are all things that will add on to the issues of like you receiving the medical care.



**CELESTE WATKINS-HAYES** [00:24:03] Right. Right. Because you're layering on another level of stigma for people who are already dealing with what I call "intersectional stigma". Michelle Tracy Berger has that term "intersexual stigma". It's so accurate. Right? So it's not just one category of stigma. Right? Being a sexual minority or queer person. It's that plus being black. Plus maybe being poor. Right? Maybe. So how do you then navigate a system in that context where you have very little privilege, you have very little say over, you know, how you navigate a system. And I think people underestimate how for people who have resources and are privileged, how systems open up for us. Right? How we have all kinds of ways to navigate, to get what it is that we need. We know how to call people. We know how to assert ourselves. And there's a way in which the world is trained to respond to people with resources. And it's also trained to not respond to people with few resources. Right? So what happens too often is for people entering that medical space, you know, first of all, can they get access to an appointment? Can they get access to a provider who's non-judgmental? Can they get access to a provider who's going to help them understand what that diagnosis means?

**JVN** [00:25:20] Which for anyone with HIV, I think in 2019. At least, well, I can speak for myself in 2012 when I found out. Me even being a white person. I mean, I wasn't, I definitely wasn't poor, but I definitely wasn't like not where I am now and definitely by no means comfortable. Like I had to, like kind of lie, cheat, steal to get that last like, you know, a couple thousand like from the family. Then after that I got cut off like a dead foot. So like that's kind of where I was. And so like that there was like Ryan White. Then there was like. And I knew that when I was diagnosed in Missouri, they didn't have a state program that was like that I at all could even start to navigate, it was so confusing. But when I started when right after I got diagnosed, I was like, well, the doctor said something about California. So I was like, let me Google California HIV stuff. And like so there, I was like, OK, that actually is like, I just need to sign up for a ADAP. Sign up for HF, sign up for my Ryan White funding. I can, and sign up for Medical. And if I sign up for those four things, I will. I can see a light.

**CELESTE WATKINS-HAYES** [00:26:16] Right.

**JVN** [00:26:16] But even signing up for those four things. I mean, I think I ended up like crying in front of a computer screen in the fetal position like four times on each sign up because it's like if that screen gets Xed out or if anything happens like or if you do all of your information, but then like you might press "send" and then it might just like the spinning pinwheel of death forever and it doesn't go through.

**CELESTE WATKINS-HAYES** [00:26:33] Yeah.

**JVN** [00:26:33] It's like, it's a lot of stuff to coordinate and jump through for anyone.

**CELESTE WATKINS-HAYES** [00:26:36] Yes.

**JVN** [00:26:37] But if you don't even have access to the fucking computer.

**CELESTE WATKINS-HAYES** [00:26:39] Exactly.

**JVN** [00:26:40] Like if you can't even get to the computer to attempt to sign up for these things, or you're doing it for like the library hours. Like you don't even have a computer to get to.

**CELESTE WATKINS-HAYES** [00:26:45] Right. Or to know I'm in Missouri. But if I go to California then I get, or if I move or all of that. All of these different barriers. And also we've got to talk about the stigma. Right? So this idea of. Is it easier for me to live in denial, live in silence than to grapple with all of that and with all, with what it means? Because what happens when I tell my family? What happens when I tell my friends? And particularly if I'm a minority who's already living in a context where my family, my friends and my community is everything because the outside world has given me hell. Then the idea that I may be cut off from that. Right? That I may be stigmatized by the people that I love the most, is going to be painful for every, anybody. But it's really going to be painful. Who rely on us, a social structure within our larger social structure. If they feel like the larger society marginalizes them and oppresses them. So making sure that, you know, you're thinking about how do I navigate this stigma is a really important issue for people who are already marginalized.

**JVN** [00:27:55] Now, this is like really, really kind of, well It's terrifying because so when I found out that I had it. Like going into like a denial space or like not getting treatment, like didn't feel like an option because like what we know medically and what I knew then was that like, if I choose to not get on pills for like ever, like I'm going to die eventually, like that's what the options are. It's like it might not be tomorrow and it might not be in like a month, but like your HIV virus, unless you're like one of those very few lucky people who are what's called like a nonprogressors. And there is like this like point 00008 percent of people who are living with HIV who like don't have to get on pills for a really long time. And they kind of stay undetectable because like it just doesn't progress in their system. But that is not normal. Like that is not the usual thing. Most people, if you fi-, if you have HIV and you never get on medication, you're gonna develop a really high viral load. And the higher your viral load is, like the easier it is for you to transmit the virus. So from like a public health perspective of like, OK, we want to make sure that like everyone who has it knows that they have it so that they can get on their ART therapy and like, you know, make sure that, because we know what ART is. I hope if you're listening to this podcast at this point, you know, what it is. But really quickly, if you don't. ART is what you take. It's what I take every day. It's like it can be one pill a day can be two. It can be three. A lot of times it's one, though, when you take it once a day and it keeps your virus undetectable in your blood so that sexually you're not at risk of transmitting it. And so it does make, essentially it makes the risk of you being able to sexually transmit your virus when you've achieved and maintained an undetectable viral load, which is what that means when you're on ART therapy. You're probably not going to spread it. But if you're someone who knows that they have it and you're not on medication, it's obviously concerning for like a public health thing. But it's also concerning for you personally because there's a lot of draconian laws on the books that like if you have it and you're like per-, like passing it around like that is an issue. Like, I mean, for the person who has it in for their sexual partners, there's a lot of issues there.

**CELESTE WATKINS-HAYES** [00:29:46] Right. HIV criminalization laws, yep, are still a thing. Yeah.

**JVN** [00:29:49] In like so many states.

**CELESTE WATKINS-HAYES** [00:29:50] Yeah.

**JVN** [00:29:50] I know California, they just kind of reduced it to be like a misdemeanor. So it's like not where it was, but it's like I think the point is, is that like. I can't, the, before I got off track, 'cause I like, got my brain just like "gegegeee". But it's like I can't imagine thinking, like I'm going to live in denial and just like, not get on pills and just like, pretend like, I don't know that I have it, that that would be less fearful to do that than to just go find the resources.

**CELESTE WATKINS-HAYES** [00:30:15] And take the pills. Yeah. So in my book, "Remaking a Life: How Women Living with HIV Confront Inequality". I lay out this framework called "Dying From to Living With to Thriving Despite". And we can think about this is dying from HIV to living with to thriving despite. But really, as I talk to the women. They were dying from so many other things, right? They were dying from the aftermath of childhood sexual trauma. Right? And struggling with that. They were strugg-, dying from mental health challenges. They were dying from poverty. They were dying from stigma. They were dying from lack of access to so many different things. So what was truly surprising to me was the number of women that talked about HIV is not the worst thing that's ever happened to me. So if you're living in that context of multiple challenges and disadvantages, HIV might not be the thing that you prioritize to address first. You might be grappling with an addiction. You may be grappling with severe depression, anxiety. You may be homeless. Right? So those might be more pressing concerns such that you don't immediately get on medication. And the other issue is just absorbing the fact that you're living with HIV. And for people who see, who are asymptomatic, their view may be, well I don't feel sick, I don't look sick. I'm just going to, you know, pretend like it's not there or grapple with my other challenges first. And what I talk about in the book is, you know, how do women move along the trajectory? How do they move out of that place to say, okay, I'm going to get on meds, okay. I'm going to go see my doctor. Okay. I'm going to manage this as the manageable chronic illness that it is instead of the death sentence that I believe it to be? And what moves people along the trajectory are two things. Number one, the cognitive shift. So for you, it was it sounds like it was pretty immediate, like you got diagnosed. So you said, OK, I've gotta, you know, address this. And it might have been tied to other things that you decided to do around, you know, life changes and moving and addiction and grappling with, you know, your experience with sexual trauma. But for everybody, it's got to be the cognitive shift. So for some women, they say something like, I just got tired. I just got sick and tired of being sick and tired or I realized that I wanted to live for me. Or they'll say I realized I want to live for my family. Right? Because they had been doing things to please other people and they decided to put themselves first or they recognized what it would mean if their families lost them. So the cognitive shift is critical, but it's not the only thing. It's not just about waking up and saying, oh, I'm going to manage my HIV status. It's about the second thing, which is the HIV safety net. So your point about-

**JVN** [00:32:57] Before we get it, because they have to list-,well you guys don't have to do anything. You could turn this off right now, but you shouldn't! Actually, I don't want to shame you. Please listen to the rest of our episode. We just, we have to take a really quick break. We'll try not to any British accents on it, I swear. Just listen to two quick commercials and then we're gonna be right back with more Dr. Celeste Watkins-Hayes after the break. Welcome back to "Getting Curious", this is Jonathan Van Ness, so what we were about to get into, which is so important is so step one was the cognitive shift.

**CELESTE WATKINS-HAYES** [00:33:37] Yes.

**JVN** [00:33:38] Step two is?

**CELESTE WATKINS-HAYES** [00:33:39] The safety net. Oh, my gosh.

**JVN** [00:33:42] I think we should talk of that. But just sidebar, just so that you can decide how you want to answer. Safety net. Yes. I'm also curious about like how you decided to write this book where you were, like you're minding your own business.

**CELESTE WATKINS-HAYES** [00:33:52] Oh sure.

**JVN** [00:33:52] You're like a Northwestern, like you're working with people in the like. I need to write this book. Like, I'm also curious about all that, and like how you wrote it, everything that went in to it.

**CELESTE WATKINS-HAYES** [00:33:59] And we should talk about The New York Times op ed. And how I wrote that.

**JVN** [00:34:03] And all that too.

**CELESTE WATKINS-HAYES** [00:34:03] Yeah.

**JVN** [00:34:03] Yes, everything.

**CELESTE WATKINS-HAYES** [00:34:04] And how you inspired me. Yes, totally. So I've interesting story about that, too. OK. So the HIV safety net. So I have to figure out as a writer, how do women move from dying from to living with to thriving despite? Why does some people stay stuck and dying from? Why does some people progressed to thriving despite? And what explains that trajectory? And I think it's the cognitive shift. But I also think that it's the power of the HIV safety net. So what's the FDA-, HIV safety net? You actually explained it. Being able to get access to Ryan White Care Act, Medical Assistance, AIDS Drug Assistance Program assistance, that gave you access to medications. But in addition to the health care, the HIV safety net also offers a ton of social support for people living with HIV. So whether it's case management, support groups, peer counselors. I mean, just the work that you're doing on this podcast and the work that you've been doing on your book tour, you're offering social support to people by giving them information, by giving them a language to talk about what's happening to them, that you can live with HIV. It's not a death sentence. To talk about what it means to say I'm undetectable and I'm therefore sexually untransmittable. So the safety net provides people with that information. And it also provides people with sometimes access to economic assistance. So, you know, whether it's getting access to government assistance or helping people find jobs, helping people find access to job training, giving them tools, working with an HIV agency, answering the phones can sometimes lead to people moving up in HIV organizations and getting employment that they wouldn't have access to. And the fourth thing that the safety net does, which is really, really powerful, is it provides an on-ramp to political and civic engagement. So people who never imagined themselves to be agents and actors in politics, who never imagined that they would be explaining to politicians why we need to support the Affordable Care Act or the Ryan White Care Act and why we shouldn't defund Planned Parenthood and why we have to really think about how do we have a national HIV strategy. The people who have been voicing that to politicians are often people living with HIV who learned through being active in the movement how to do that. And it goes all the way back to the activism in the 1980s. And, you know, we used to see AIDS activists on our evening news all the

time, but they're still out there. We don't see 'em on the news as much, but they're still out there. And it's rooted in, you know, work that you saw coming out of the LGBTQ liberation movements, barring many of the tactics of the civil rights movements in the 1960s and 1970s. And it's a movement that's still alive and that is still fighting to make sure that, you know, one-, when you plug in access to HIV services into your computer, after you get diagnosed, you get all of this information. People had to fight for that and people continue to have to fight for that. So the HIV safety net trains people on how to do it so that they can empower themselves, but they can also be a force for in the empowerment of other people. So it's a really powerful entity. It's not as you know, my wish for it is that it's present wherever it's needed. Right? So it may be strong in our major cities, particular major cities in the north. In the south, a pretty weak HIV infrastructure that's ramping up. And I just heard a great talk yesterday about the work happening in Alabama. But we've got a long way to go to make sure that that safety net is robust where ever it's needed in the country. But I can tell you from doing my research, it is absolutely critical for women living with HIV to have access to that safety net.

**JVN** [00:37:54] So how is the safety net served or underserved women? I mean, cause it's like we hear like I mean, where I used to go at AHF in California, like it was mostly gay men. And also we, we saw trans folks that were in our clinic. But I, I typically did not see like people who looked like-.

**CELESTE WATKINS-HAYES** [00:38:14] Cis gendered women. Yeah

**JVN** [00:38:15] Yes, I didn't want. But like.

**CELESTE WATKINS-HAYES** [00:38:16] Yeah.

**JVN** [00:38:16] So it's like how had-? Because I mean, I feel like the stigmatization around like gay men, queer people, it's like, OK, like you. It's not the first time like we're, you're seeing your friend at AHF. Like, it's like, okay, you got it. I got it. It's like it's it's. It's a little bit more like, I feel like the stigma within the gay community, it's bad, especially like on Grindr and stuff, but like in the, like, I wasn't like having to like, you know, where my hat and like glasses going to the doctor's office. If you are in a small town or you're in a place where it's like it just seems like the stigma affects people differently.

**CELESTE WATKINS-HAYES** [00:38:46] Absolutely. Absolutely. There's a way in which within the LGBTQ community. The community identified HIV as an existential threat very early on in the epidemic, partly because of how it was framed. The first cases were found in previously healthy gay men. But part of it was the ownership that the community took over HIV to see, see it as this could kill us if we don't manage it and control it and find ways to fight back. So there was a kind of political emergence that happened within the community. Now I'm going to complicate that narrative. Black and brown gay men were always part of the story. Black lesbians, you know, black and brown LGBT folks were always part of that movement, but somewhat marginalized on the basis of race. But when we think about the black straight community, really reluctant to take up the issue of HIV as an existential threat. Number one, the black community was dealing with so many other things. It was like stand in line. The second thing was that and Cathy Cohen writes about this really well, the political scientist, and African-American studies scholar. There was a luctant-, reluctance on the part of black political leaders to own HIV because it was about sex. It was about drugs. And the civil rights movement strategy, up to that point, going back to our conversation about slavery and Jim Crow. The way to fight back against that had been largely to adopt a politics of

respectability. So that means look at the way that we fight this oppression is we're going to act right, talk right, do everything 10 times as better and then we'll get our rights and we're going to demonstrate that we are wonderful salt of the earth people who absolutely deserve our rights. And when you think about, you know, everything from, you know, Jackie Robinson and his very kind of pristine profile to how civil rights leaders often promoted, like I'm a family person and I'm doing all these great things in the community. And it was often led by pastors. You know, that was about respectability. Right? As a strong-, a political strategy. That gets challenged when the face of HIV are people who are using drugs, are people who are gay. And we've got all these kind of religious teachings of how do we confront that? How do we think about that? When we're talking about transgender individuals? So because they didn't fit the respectable narrative, there was kind of a reluctance to take this on as an issue. And the idea of talking about sex and demanding political rights around sex, when black folks already get accused of being hyper-sexualized and problematic about sexuality and etc. and we're gonna claim this as a political cause. No, thank you.

**JVN** [00:41:46] Felt too much of a hot potato.

**CELESTE WATKINS-HAYES** [00:41:47] It was, it was way too much of a hot potato. So what happened as a result was silence.

**JVN** [00:41:53] And actually silence is like what makes the ripple effects of HIV like tidal wave.

**CELESTE WATKINS-HAYES** [00:41:57] Exactly. Exactly. And on the other hand, you also had while the predominately white LGBTQ community is taking the NIH and the CDC and other government organizations to task and demanding resources, black communities are not getting the resources that they should be getting access to. So it was this twofold thing.

**JVN** [00:42:15] Just like anyway?

**CELESTE WATKINS-HAYES** [00:42:16] Right. Like we don't want to talk about it. And then the discrimination. And also, there's not necessarily an active social movement is making it so that as the, as the resources are being divvied up, black communities and brown communities are getting under-resourced and under-resourced and under-resourced and under-resourced. Right? Because when black folks do show up in the HIV conversation very early on, it's in a very problematic ways. It's oh, it's all these people coming over from Haiti and they're infecting people. It's very much kind of a boogeyman, othering kind of conversation. It's oh, all these black people are using drugs. So how do you grapple with that politically within the epidemic? So you get the under-resourced issue coming through institutions like government institutions and also kind of the HIV non-profits that are starting that aren't necessarily paying attention to black communities in the ways that they should. And then you got silence on the part of the black community and then you've got these small army of black HIV activists who are fighting the good fight with very few resources at their disposal. And that was another kind of key point of how did we get the disparity? Right? That we still grapple with today. So we're dealing with the legacy of slavery and Jim Crow, but we're also grappling with how do we respond to the epidemic at the beginning and how are we still catching up to respond to the racial inequality?

**JVN** [00:43:43] Because it's almost been 40 years.

**CELESTE WATKINS-HAYES** [00:43:44] Yeah, yeah, yeah.

**JVN** [00:43:46] I just had to hold up my fingers to like-.

**CELESTE WATKINS-HAYES** [00:43:47] Absolutely. It's almost been 40 years. So we're seeing, you're seeing a lot more conversation about HIV in black communities. I think, you know, you can't underestimate the power of Magic Johnson, who, you know, was a key framing device for a lot of black folks of like, oh my gosh, Magic too. This is an issue we need to be thinking about. But for women, coming back to your question, they've then, how did they find their way within this? Right? Particularly cis gender straight black women. If they're not part of the LGBTQ community and they're within the black community, but the black community is challenged in different ways in terms of how its thinking about the epidemic and the resources that it's getting to fight the epidemic. So black women end up just kind of getting lost in the narrative. Right? And we would add cis gender white women as well, just kind of end up getting lost in the narrative.

**JVN** [00:44:37] Because especially if and this is the other thing, so it's like, you know, that that whole thing of like, oh, the fastest growing community of newly infected HIV positive people is like black women between the ages of 18 and 34. Have you ever heard that whole thing?

**CELESTE WATKINS-HAYES** [00:44:48] I heard that. That right now, though, I think it's black gay men within that age group. And that was a statistic that I heard that inspired me to do the research. So that was probably like early 2000s. And now the, I believe the fastest growing group are young black gay men and bisexual men. So black women, it's interesting. You know, they've always been part of the movement, but a small part of the movement. And you may ask, like, why haven't they been more visible? Well, it was really interesting in my research, women talked about-.

**JVN** [00:45:23] Because what it is you're, tell people what your book-.

**CELESTE WATKINS-HAYES** [00:45:25] Oh, sure.

**JVN** [00:45:26] Yeah.

**CELESTE WATKINS-HAYES** [00:45:26] So I interviewed 200 people around the-, of just about 200 people around the HIV epidemic. So I interviewed over 100 women living with HIV in Chicago. So women of diverse racial and class backgrounds in the city of Chicago who talked about this movement that they experienced from dying from to living with to thriving despite. And then I introdu-, and then I interviewed the activists and policymakers and service providers who were part of the building of the HIV safety net. Because I needed to understand, like, what is this entity that women pla-, kind of plug into? And that proves to be transformative for them. You know, when they talk about, the first line of my book is kind of controversial. I say I quote a woman named Dawn who tells me if it weren't for HIV, I'd probably be dead.

**JVN** [00:46:18] I feel like that, too, sometimes.

**CELESTE WATKINS-HAYES** [00:46:20] And why do you feel like that? I bet it's why she feels like that.

**JVN** [00:46:23] It's because if I hadn't realized that I was positive, I was going to probably keep doing like self-destructive crazy shit until I would have like died of like an overdose or been killed or like HIV was what stopped my downward spiral.

**CELESTE WATKINS-HAYES** [00:46:37] That's what she says, too. So Dawn talks about, you know, she was homeless on the street, in addiction, really struggling. And she got diagnosed in 1985.

**JVN** [00:46:47] Holy shit.

**CELESTE WATKINS-HAYES** [00:46:47] But didn't know what it meant. And the doctors didn't really give her more information, much information. And she ends up kind of living on the streets for about, you know, 15 years and she finally gets in to care and treatment and it's the safety net. She gets access to a community, to health care, to mental health services that she needed because she was a survivor of childhood sexual trauma. She meets her life partner. She gets access to economic resources. And she ends up becoming a very powerful leader in the HIV community. She ends up meeting with Nancy Pelosi. I mean, like she is doing the thing in terms of local and national HIV leadership. And that's why she's saying that. Because what you're really saying I think if I'm hearing you correctly, because I notice what she's saying is if it weren't for the HIV community and if it weren't for that moment of are you going to live or are you going to succumb to all of the challenges? And you need to decide what's it going to be. And in that moment, she decided and you decided, I'm going to fight like hell and I'm going to live. And it's what I really hope people understand is that alone is not enough. And in our politics, we just assume for so many people who are struggling, well, why don't you just get it together? What we've got to understand and what my book I think really demonstrates is there has to be a safety net to catch you so that when you decide I'm going to do things differently, I'm going to push myself to move from dying, from all of the things that you were dying from, because you were dying from all those things. Right? To living with, there's gotta be a support system, a community to move you along the way and to help you.

**JVN** [00:48:36] And like in my case, I had the resources and the privilege too like there was a car I could drive. There was someone I could lie, cheat and steal that four grand from to get to California. Like if you're not in that position to have the computer or to get your hands on the car or to get you-

**CELESTE WATKINS-HAYES** [00:48:50] To leave the state.

**JVN** [00:48:51] To leave the state to get to-

**CELESTE WATKINS-HAYES** [00:48:52] To go to higher resource state.

**JVN** [00:48:54] Than you're, than like then these things-. That's why some people can't get it together like so-.

**CELESTE WATKINS-HAYES** [00:48:58] And that's why exactly.

**JVN** [00:48:58] 'Cause they are like and there are so many layers to this that make it so, that make it so difficult from stigma to racism to cultural pain bodies that make it so difficult for people to get treatment.



**CELESTE WATKINS-HAYES** [00:49:10] Right. Absolutely. Absolutely. And we can't underestimate the power of trauma. Yes. So-

**JVN** [00:49:21] So then?

**CELESTE WATKINS-HAYES** [00:49:22] So then I publish this book and I'm on Twitter. Don't let anybody tell you that Twitter is a total waste of time. And I get The New York Times and I saw your op ed and I said, oh, I need to read that. And I flagged it. And then the next day, it came up again on Twitter. And I said, OK, let me read it. So I'll never forget it was the day of the Emmys that I read it and I read your story. And I said, oh, my gosh. Jonathan Van Ness could've been in my book. So obviously, you know, I wrote about women in the epidemic, but the story was so similar when I read Alex Hawgood. I hope I'm saying his name correctly. The great reporter. His profile of you, because I saw so many of my women's stories in your story. In terms of your history of of sexual trauma very early in life, your struggles with addiction and being diagnosed and having to figure out what do I do now? And the importance of the safety net, the way that Planned Parenthood caught you and gave you that diagnosis and the way in which, you know, people in your life, in your community were helpful. And the HIV community ends up being very helpful for you as you move from dying from to living with to thriving despite. So I read it and I said, oh, my gosh, basically this is my book. So I immediately go to my computer and I just start typing and I happen to have a contact at The New York Times, a fabulous editor, and wrote to her and said, I just wrote this op ed. Would you consider it? Send it to her. And she said, we'll consider it. And, you know, anybody who's ever tried to publish an op ed anywhere knows it's a very, like, you know, nail-biting experience as your waiting. That night, the Emmys were on. And Billy Porter won the Emmy for best actor for "Pose". And I just thought it was so powerful in terms of me reading your story. Me seeing your book in, seeing my book in that story and the synergy and the connection. And then Billy Porter winning that Emmy for "Pose" and the work that "Pose" is doing to also talk about the epidemic in really powerful ways and to show what it was like in the 80s and the 90s for black and brown people and particularly for trans women and how they were so isolated within, within the epidemic and within the community. So it just kind of all came together. And I'm really grateful that I had the opportunity to, to hear your story. And that so many other people have had that opportunity, because the lives that you're changing that you'll know about, but the lives that you have changed that you will never know about is simply astonishing.

**JVN** [00:52:24] Much emotish. So, yeah, I mean, I think writing the book and the tour, it was like I didn't, I guess I, I think I was waiting for like I thought I didn't know how I was going to be received. And I was obviously nervous around. And that's what the whole crux of my book is, is like, would you still love me if you knew, like all the fucked up stuff that I've done and all the hard things I've been through? But really, I think the hardest part of it has been realizing how many people are still suffering and how many places the social safety net is not.

**CELESTE WATKINS-HAYES** [00:52:54] Yes.

**JVN** [00:52:55] And there's so much work and so much brought to my attention, like after the book where I'm like, oh my God, like, if I thought writing that book was hard and going through the release of that was challenging, like, honey, get ready for the rest of this journey. 'Cause it's like it, I mean, we've made a lot of strides but like we still have, I still have so much more work to do in increasing awareness and in, in helping expand the safety net as far as I can.

**CELESTE WATKINS-HAYES** [00:53:16] Yeah. And the beauty of the community is you don't have to do it by yourself. So I don't know if you need this advice, but I'm just gonna say it and hopefully it'll help somebody else. Don't feel like you have to do it all alone, right? Because that's the other thing that my book highlights is, you know, when I think about women who were founding HIV organizations, I'll think about, say, Pat Nalls in Washington, DC, founding the Women's Collective. It started off with her going to support groups and feeling like she really liked the men that she was in the support groups with. But they didn't have the same issues. They weren't rushing home to relieve the babysitter and having to pay somebody childcare costs to be able to come to the meeting. So her kind of putting out a kind of feeler of I'm looking for other women, brought other women into community and looked at what they can do together. So I think that part of it is you shared your story and then I wrote the op ed. Other people have talked about your story. It kind of blossoms and grows and other people can kind of carry it with you. To create this larger message of this is a safety net that has made enormous strides. Like, you know, there's a way in which HIV can be very much a doom and gloom story. And that's part of it. But if we think about in 40 years, we've moved something from a death sentence to a manageable chronic illness where undetectable equals untransmittable like they're not. If you take the long view of history, there are not a lot of social problems that make that much progress in that kind of period of time. So we got a point to what if we do that worked and it was building the safety net and it was also working through the difference and the diversity within the safety net. So how is it that white gay men and black trans women and, you know, Latina cis gender women, you know, women can come together and work on an issue. There's some lessons here in terms of how a lot of different communities can come together and move the needle on something together.

**JVN** [00:55:25] Another thing that this keeps highlighting for me in my head and then I'm going to give you yoji recess, which is where you can say whatever you want, then we'll wrap it up.

**CELESTE WATKINS-HAYES** [00:55:31] Yeah.

**JVN** [00:55:31] Is when we talk about, you know, HIV is a disease of inequality. And then I think about the Equality Act, which would ban discrimination at federal level on bases of housing, credit applications, education, jury selection. But those first three things were really big. Housing, education and then access like credit, like, you know, playing for credit, things like financial. And it's like those are three things where like, you know, there's certain states where those are already on the books that there's places in a lot of states where that is not. And you can. And let's say you do get discriminated against on basis of housing and say like in Alabama or a place where it's like not like where the Equality Act, we would need that to like to cover you. Because like, but like, I guess equality after, or the Civil Rights Act already says that you can't discriminate against housing, education and whatever on basis of race. But people still do.

**CELESTE WATKINS-HAYES** [00:56:24] Absolutely.

**JVN** [00:56:25] And the Equality Act for people that are trans, gay, lesbian, transgender, LGBTQ plus, that's what we want the Equality Act to cover is to cover all of those things. But it's like for the I guess what I'm noticing is like for the marginalized communities that are both that are already a person of color and trans or a person of color and queer, it's even more important for them that we get the Equality Act passed because that will help, too. It seems like that would start to help to bring together some of the inequality that's facilitating the disease.

**CELESTE WATKINS-HAYES** [00:56:53] Absolutely. And you know, if people particularly, you know, part of what was so important about the HIV movement and continues to be important is the way in which marginalization and privilege work together within the movement to push the agenda forward. So absolutely, the experience of marginalization fuels a lot of what the issues are, who's most affected, how we fight. But it's also the ways in which, let's be honest, white gay men used white privilege and male privilege to move the needle because part of it was they looked like the face of power. Right? So, you know, I always chuckle when I look at, you know, movies like "How to Survive a Plague". And I look at the ways in which the activists are taking over federal buildings and climbing up on buildings and protests. And I always think to myself, Lord, if that would have been some black activists who were, and there were black activists who did that, but would they be gently helped down the building by the police? Would they be taken to police headquarters, booked, but then let go? Would there be another level of violence that would have befallen the activists if the face of HIV activism was exclusively a black face? Because we know the history. Right?

**JVN** [00:58:17] Right.

**CELESTE WATKINS-HAYES** [00:58:17] You know, just look at footage of the Civil Rights Movement and how the protesters were hosed down.

**JVN** [00:58:20] Right.

**CELESTE WATKINS-HAYES** [00:58:21] And subject to dogs and all that other kind of stuff. Slightly different era, but still.

**JVN** [00:58:25] But now that clo-, not that far.

**CELESTE WATKINS-HAYES** [00:58:26] Not that far, not that far.

**JVN** [00:58:27] I mean, the 60s to '82, it's like.

**CELESTE WATKINS-HAYES** [00:58:29] Exactly.

**JVN** [00:58:30] That's younger than me.

**CELESTE WATKINS-HAYES** [00:58:31] And even if you look at current protests around, you know, the movement for black lives in terms of how the protesters get treated.

**JVN** [00:58:36] Oh, my God.

**CELESTE WATKINS-HAYES** [00:58:36] It's very, very different. So there's a way in which we have to be honest about the way in which white male privilege had a really profound effect on the progress that was made. But how also minority status on the basis of sexuality and race and gender and class also helped to fuel the movement and be that. And I think that's the special sauce, right? That those two things ended up working in tandem. And there's conflict and there's tension and there's, you know, call outs and fights. But somehow the community figures out how to focus on the goal of fighting the epidemic and moving forward. And I think that there's lessons for all of us. It's about

centering all of our stories and figuring out how do we speak true to fight to, how do we speak truth to power, to fight something that is essentially an epidemic of inequality?

**JVN** [00:59:31] Dr. Celeste Watkins-Hayes, I just can't only talk to you for 50 minutes on this subject. We're going to have to have you back.

**CELESTE WATKINS-HAYES** [00:59:37] Yes.

**JVN** [00:59:37] We really well, I mean, you're just so incredible. And thank you so much for your work and for your time. Is there anything that we missed that you could get into like a minute's time that you just want-, obviously we need to listen to the book.

**CELESTE WATKINS-HAYES** [00:59:47] I was going to say. This is this is completely random. So, yes, I would love people to read my book, "Remaking a Life: How Women Living with HIV Confront Inequalities". It's available at all your booksellers.

**JVN** [00:59:57] Is it on audio too?

**CELESTE WATKINS-HAYES** [00:59:58] It's on. I would like to put it on audio and maybe you can help me with that. I would like to get it on audio, but it's on Kindle.

**JVN** [01:00:04] You have a great voice, queen.

**CELESTE WATKINS-HAYES** [01:00:05] Thank you.

**JVN** [01:00:05] I mean, I would listen to the shit out of your book.

**CELESTE WATKINS-HAYES** [01:00:08] Thank you. Thank you. Thank you. But I have to say. So I did, you know, I was already a fan of yours, but I'm doing, you know, my research in the process of the show. And one thing that all of my friends talked about when I said I was going on your show was the episode of "Queer Eye" where you worked with Wanda.

**JVN** [01:00:24] Oh, my god, I love Wanda.

**CELESTE WATKINS-HAYES** [01:00:26] And for those who need a refresher, Wanda is an African-American woman that was dealing with alopecia.

**JVN** [01:00:32] Alopecia. Yes.

**CELESTE WATKINS-HAYES** [01:00:33] And-.

**JVN** [01:00:34] Traction Alopecia. Yes.

**CELESTE WATKINS-HAYES** [01:00:35] Yes. And, you know, I was so fascinated by that episode because I stopped, I stopped relaxing my hair probably 10 years ago. And I go back and forth sometimes I blow dry it out like today. And then other times I'd I'd twist it and wear it curly.

**JVN** [01:00:50] Oh, love.

**CELESTE WATKINS-HAYES** [01:00:51] Yes. If you have me back, I'm gonna wear it the second way. So you can see both, both styles. But one of the things I was so curious about is what did that episode teach you about black women through the conversation about hair? Not to generalize to all black women, but I bet you got an interesting learning experience about the legacy of hair for black women.

**JVN** [01:01:14] Well, it's interesting because I don't think I could have ever gotten into that episode not having had like an extensive history and experience of working with black women and working with textured hair as a whole. Like when I went to hair school in Minneapolis, a huge portion of my clients were Somalian women that, like 'cause Minnesota was like one of the only states that takes Somali refugees. So like, I really learned how to do hair on textured hair generally like when I was a teenager. And then. But I think, you know, moving to Arizona and working in an, Arizona, didn't have too much textured hair. But then coming to Los Angeles, when I assisted in Los Angeles, I had a lot of textured hair and I experienced a lot of traction alopecia from clients in the music industry, just from around that were like kind of constantly chasing this hair texture and this hair looked at like was not their natural texture. And that was on brown women, that was on black women, that was on white women who had like thinner hair. So I saw like the whole traction alopecia thing on like several different races of women. But it was always from weaves and just braids that were like not replaced enough, not changed enough, like too tight. And but, it was from this, this unrealistic expectation of beauty, because no matter what your skin color is, you're not meant to have like eight pounds of hair sewn onto your head for five and six and seven weeks at a time. Maybe a week, not six and seven and whatever. But I think what I've always thought was in beauty and in magazines and in the industry, it's like we teach people that our music videos like, oh, you just go get your hair done. It looks like that. No, no, no. That model or that person that you're seeing without hair was in hair and makeup for like hours. This is like thousands and thousands and thousands of dollars that we're spending on these looks. Or like what these companies are spending on it or it's photoshopped or it's a wig and you, or you think it's braids but it's like there's like a lot. So really, it's, I didn't learn it in Wanda's episode specifically, but it was driven home. But it's like that this idea that like thick, shiny, smooth hair that lays down is what's the most, is what's the most desirable. And my thing has always been like. Whatever you got is the most desirable.

**CELESTE WATKINS-HAYES** [01:03:12] Yeah. Yeah.

**JVN** [01:03:12] Like, I love it. But that has been institutionalized within us that this certain type of beauty and it's actually interesting what you're talking about, about the respectability.

**CELESTE WATKINS-HAYES** [01:03:19] Yeah.

**JVN** [01:03:19] That's when relaxers were like really coming out with like in the 60s and 70s and 80s so that we could like, you know, make the hair look more like-

**CELESTE WATKINS-HAYES** [01:03:26] Right. Where you would chemically, for those who don't know, you basically put a chemical in your hair that would relax your hair. And it would burn in their skull.

**JVN** [01:03:33] But we're still seeing this now with these recent-. Like we're, like a, like women of color can't wear their hair this way or that way. We're finally starting to get, like in California, I think they just pass a law where you can't-.

**CELESTE WATKINS-HAYES** [01:03:41] Yes, where you can wear it, where they can't discriminate on the basis of how they're, how you're doing your hair.

**JVN** [01:03:45] So we're starting to think about this conversation. But I think there's there's a wider unrealistic expectation of beauty, spe-, period. For women.

**CELESTE WATKINS-HAYES** [01:03:52] Yeah.

**JVN** [01:03:52] But for women of color.

**CELESTE WATKINS-HAYES** [01:03:53] Yeah.

**JVN** [01:03:53] It's a whole other layer of ridiculousness and it's like-. So for someone like Wanda that was like, you know, like I mean, she was dealing with like really severe it like I mean, it's not just Wanda, there's women all over the country that are having really significant traction alopecia from sewing stuff onto our scalp covering-, because it would be like sewing a washcloth over your face and thinking that your facial skin was gonna be like, okay, after six weeks.

**CELESTE WATKINS-HAYES** [01:04:17] Oh Okay.

**JVN** [01:04:18] No, like our scalp skin is very slim. It's like we can't put like a cloth with a bunch of hair over, over our face skin and then take it off in eight weeks and think your skin is gonna be like happy. No.

**CELESTE WATKINS-HAYES** [01:04:25] Right. Yeah.

**JVN** [01:04:26] All upset.

**CELESTE WATKINS-HAYES** [01:04:27] Yeah.

**JVN** [01:04:28] So but although, but like Wanda looks amazing and she's still doing so good. I just saw her on the kids city book tour.

**CELESTE WATKINS-HAYES** [01:04:34] Oh good! And it was so courageous of her. So shout out to Wanda.

**JVN** [01:04:35] So courageous.

**CELESTE WATKINS-HAYES** [01:04:37] And that drill team was so fierce.

**JVN** [01:04:39] They slay so hard. They love Wanda so much. But Dr. Celeste Watkins-Hayes, thank you so much for your time. I appreciate it so much.

**CELESTE WATKINS-HAYES** [01:04:44] Oh, what a joy. Thank you so much for having me on the show.

**JVN** [01:04:46] Thank you so much for coming.

**CELESTE WATKINS-HAYES** [01:04:47] Okay.

**JVN** [01:04:53] You've been listening to "Getting Curious" with me, Jonathan Van Ness. My guest this week was Dr. Celeste Watkins-Hayes. Our theme music is "Freak" by Quin. Thank you so much to her for letting us use it. If you enjoyed our show, introduce a friend. Show them how to subscribe and follow us on Instagram and Twitter at CuriousWithJVN. Our socials are run and curated by Emily Bossak. "Getting Curious" is produced by me, Julie Carrillo, Rae Ellis, Chelsea Jacobson and Colin Anderson with special guest bookings by Mary O'Hara.