

Your Health Unlocked Podcast Episode 47

HIV Must-Knows for Women in 2024 with the Positive Women's Network

0:00:16 - Adele Scheiber

Welcome to your Health Unlocked, a podcast that empowers you to make better healthcare decisions by elevating accurate, unbiased information about today's most pressing health topics. This podcast is produced by the National Women's Health Network, a nonprofit group of activists fighting for better access to high-quality healthcare across the nation. We do not rely on big pharma, medical device companies or insurance companies, meaning we answer only to science and healthcare consumers like you. If you'd like to support us in our work, head on over to nwhn.org/donate and make your contribution today.

0:01:06 - Adele Scheiber

Hi there, I'm Adele Scheiber, the host of the Your Health Unlocked podcast and the director of communications here at the National Women's Health Network.

Human immunodeficiency virus, or HIV, is a virus that attacks the body's immune system. It affects an estimated 1.2 million people in the US and can have a devastating effect on both the body and mind. This is especially true for black and brown women living with HIV. Join us for this moving panel-style interview with Marnina and Antoinette from the Positive Women's Network, or PWN, as they share their personal stories of HIV diagnosis, the latest research, finding advocacy through the PWN and how they are making a life-altering impact on policies regarding HIV. Marnina Miller is a highly accomplished human rights activist, speaker, trainer and social media strategist with a profound commitment to fostering positive change in society. She's the co-executive director of the Positive Women's Network USA. Her expertise in HIV activism has garnered significant recognition, leading to features on prominent media outlets such as Vice News, National Public Radio and the YouTube original series HIV Disclosure and Dating.

Antoinette Jones began her work with HIV advocacy in her early 20s as a peer navigator, facilitating access to preventative care and treatment for people living with and at risk for HIV. She identifies as a vertical woman living with HIV, meaning she has been living with HIV since birth. Antoinette was called to peer advocacy to combat the isolation many

people born with HIV go through. Antoinette has worked with organizations serving Black women and people of transgender experience, developing programs, advancements in healthcare services and leadership development. She also works with HIV providers to improve services for people living with HIV. Antoinette is the co-executive director of Dandelions Incorporated, a nonprofit that centers the development of people born with HIV through mentorship, trauma healing and peer-to-peer support.

Welcome Marnina Miller and Antoinette Jones to the your Health Unlocked podcast.

(Marnina) Thank you so much for having us.

Now we've probably, future me will record a little intro spiel, but why don't you tell us, in your own words, a little bit about yourselves?

0:03:27 - Marnina Miller

Sure, my name is Marnita Miller. I use she her pronouns. I currently reside in Houston, Texas. I am a human rights activist, a community organizer and a lover of folks and people. And that's a little bit about me so far.

0:03:44 - Adele Scheiber

All righty, and how are you related to? Well, we'll talk about that later. What about you, Antoinette?

0:03:49 - Antoinette Jones

Hi, my name is Antoinette Jones. I am a mother, a Black woman, an advocate, an accomplice in all things that equal, and all things that equal people's rights. I'm happy to be here, happy to share space with Marnina and you, Adele, and just excited to have this conversation.

0:04:15 - Adele Scheiber

Yeah, so tell us a little bit about the Positive Women's Network and how each of you are involved, either personally, professionally or both.

0:04:27 - Marnina Miller

All right. So Positive Women's Network USA, or, like we love to call it, PWNn, was founded by 28 diverse women living with HIV in June of 2008. PWN's founding members come from all over rural spaces, southern folks, urban folks and a wide array of ethnic groups. The youngest person in the room at that time was 21 and the oldest person was 72. And so we really have a wide array of folks who are our members. Currently, We have about 3000 members nationwide right now and currently a positive women's network I'm the co-executive director. I've been the co-executive director for about three months now.

0:05:12 - Adele Scheiber

My gosh Congratulations. That's like a recent thing. That's so exciting. (Marnina- Thank you!) that's a big deal. We have to celebrate more boss, more boss, babes, as I like to say, rather clichely, but that's so cool. Um, and then you are. You are living with HIV. Am I right about that?

0:05:31 - Marnina Miller

Yes, you are correct. I've been living with HIV for 11 years now okay, wow, that's 11 years.

0:05:36 - Adele Scheiber

That's awesome. Antoinette?

0:05:37 - Antoinette Jones

So I work as the national field organizer at Positive Women's Network, um Marnina pretty much covered our herstory while we do this work. I think it's good to mention, as Marnina said, like she is the co-ED and of lived experience, that our organization is ran by women living with HIV and for women living with HIV.

0:06:01 - Adele Scheiber

OK, so is that like a requirement of the organization?

0:06:05 - Antoinette Jones

Well, we are members led, so we believe that the power should be in the hands of the people who are most impacted by HIV. So, of course, our mission is to prepare and involve women with HIV in all levels of advocacy and policy and decision-making. So that's why you would see, our leaders, our co-EDs, are both women with HIV. Majority of our staff are people living with HIV and our members are women with HIV, cisgender and transgender.

0:06:39 - Adele Scheiber

Wow, that's really impressive and powerful. I think. Nothing about us, without us, is really put into practice at your organization. And does that extend to you as well, Antoinette?

0:06:51 - Antoinette Jones

Yes, so I have been living with HIV for 29 years. I was born with HIV, so I identify as a dandelion, formerly known as like perinatal or vertically transmission. We reclaimed our own language for how we want to identify, so we call ourselves dandelions or lifetime survivors, to center the people and the voices of folks who have lived with HIV for what we would consider our lifetime.

0:07:20 - Adele Scheiber

I love the term dandelion it's so. Is it wrong to say it's cute, but it's it's? Is there any like etymology behind that or?

0:07:28 - Antoinette Jones

The resilience of the dandelions. The person who wrote a poem called Dandelions. Her name is Mary Bowman. She was a person born with HIV who died in 2019. And if you, if anybody listening or you, would like to listen to the poem, it's on youtube, but everything that she wrote into the poem pretty much encompasses the experiences of people who have been aging for a lifetime, as well as the experiences of our mothers, who may have transitioned or, you know, had their own struggles with getting diagnosed with HIV.

0:08:04 - Adele Scheiber

Wow, that's amazing. Thank you, I learned something new today. I always learn something new as the host here. Okay, well, and so I do want to acknowledge we actually had a third person who was going to join us today, but she unfortunately was taken ill, and so you know we want to, I want to hold space for her and you know, as we say, pour one out for Olga and I will be in contact with her later. But if you guys are willing to answer the question that was meant for Olga before I realized who I'd be talking to, can you guys maybe briefly talk about your own journeys so far living with HIV and what diagnosis and treatment has been like for you?

0:08:43 - Marnina Miller

We definitely have a probably a varied difference in the ways in which we come about our treatment journeys and also our lived experience of living with HIV. Even though me and Antoinette are very close in age because of our lived experience it is so different. So I actually contracted HIV while being a college student at Texas Southern University, not knowing that black and brown women were more most impacted by the HIV epidemic, especially in the South. It was something that was, for me at the time, really devastating. Hearing the words that you're living with HIV for the first time can sometimes be very triggering, and so for me, it immediately sent me to a place of depression, because HIV stigma is ever so prevalent and real, even though we are 40 years into this epidemic. And so I didn't have a knot of knowledge. We know that girls and women folks are always trying to take over our fertility and tell us what to do with our bodies, yet no one is talking to us about condom negotiation, about STI and STD and HIV prevention, so that wasn't a conversation that was typically had in my household. My parents were more trying to prevent me from being pregnant, and so, because of that, I received an HIV diagnosis my freshman year of college. And so, (Adele - oh my gosh) yeah, it was pretty devastating for me. But long story short, I was able to turn my pain into power.

Once I met an amazing woman named Vanita Ray, who lives here in Houston, who used to be the co-executive director of Positive Women's Network, and she hosted a space for advocates to come in and teach newer advocates how to be HIV advocates, how to hold our own power, how to love on ourselves and love on our community in a whole new way. And so from there I was thrust into HIV activism and advocacy work. It's also a space where I learned about all of the ways in which I can receive treatment and care, because before becoming an advocate, I didn't even know that folks living with HIV had access to

care services called the Ryan White Care Program, where you can receive treatment, housing services, case management services, mental health services, and from there I learned about this whole pipeline of innovative ways in which to care and take care of people living with HIV. So I was able to find my own treatment through advocacy work, which is wild and within itself.

0:11:35 - Adele Scheiber

You would be surprised how often I hear that from from anyone. Honestly, um, it's almost like this has to be a full-time job for you to understand what's going on with the American healthcare system right, um, well, and, and I don't know.

so that's really inspiring to hear that that you I love that expression turn your pain into power. I've never heard that before. You know, and and we can get into this when we get to the myth busting question, maybe, but as a as a personal anecdote someday a recent friend of mine he was, he was a gay man shared that he was. You know, this was a couple of years ago that he was diagnosed and was living with HIV since 2011.

And I I'm kind of embarrassed to say this now, but I had like such fear for him, like I thought he was going to die, like I was. I messaged him. I was like, oh my God, are you okay? What's going to happen? How long do you have? You know, I did, you know? What can I do? And he was like you need to calm down, I'm fine. And then that's actually where I started to learn like, oh wait, treatment has come a long way since the 90s. So I don't know, Marnina, if you want to get into like what your actual treatment like for this disease looks like or if you want to wait, but I'd happy to open that up.

0:12:44 - Marnina Miller

We can definitely, talk about it.

Um, those were my same sentiments too. Like in 2013, I was like, okay, I'm about to die. This is it? This? Um, I don't.

I honestly didn't want to live, and so for two years I did take treatment of medicine, uh, until my sister told me that she was pregnant with my niece and in black and brown spaces, aunties are everything. And so I knew I wanted to be there for my niece. I knew that, um, I wanted to, like, see her walk and crawl and do all of the things, and so once my sister you know I told my sister like, hey, I'm living with HIV. I kept it from everyone for a really long time, and so from there I was, I was like I got to do something with my life, and so I found I

wanted a support group, but instead I found an advocacy group and thank God I did, because it was my saving grace and from there I was able to get a case manager, a social worker, who was able to help me guide through the program for a treatment. I was able to get on two pills at the time, because now I only take one pill once a day.

0:13:58 - Adele Scheiber

Really? (Marnina – Mmhm!) So no more cocktail is what I'm hearing. (Marnina -No, no!) Okay, so to back it all up y'all so really quickly, and maybe, Antoinette, you want to take this one before we continue, because that's wild. HIV stands for the human immunodeficiency virus, right, and AIDS is the advanced immunodeficiency syndrome, although I don't hear that used as much anymore. And can somebody just tell us exactly what that is and what it used to? And the treatment used to be like hundreds of pills and all kinds of infusions, like what does it mean to have an immunodeficiency virus? Just for people who may not quite understand.

0:14:31 - Marnina Miller

So HIV stands for human immunodeficiency virus. Hiv is essentially a virus that attacks your cells, your cells that help your body fight infections, and it makes someone more vulnerable to other infections or diseases. We use people first language to talk about people, so we don't say HIV infected person, we don't even use the words infected to talk about people living with HIV. We, you know, say “woman living with HIV” or “man living with HIV”, so it's important to put that person first. So, AIDS is the late-stage HIV infection. So typically, what happens -Or HIV three, because most of the time we don't even say AIDS anymore. We say HIV three or end stage HIV to talk about someone having an AIDS diagnosis. So, you can be a person living with HIV that has not -their virus has not advanced to an AIDS diagnosis.

0:15:34 - Adele Scheiber

Right. And in fact in some of those early stages you can have no symptoms. Isn't that right?

0:15:39 - Marnina Miller

Yeah. So in the early stages you can have no symptoms at all, and typically when someone does receive an AIDS diagnosis, it means that they've had two or more comorbidities that may impact their body. So a person that's living with HIV will progress to an AIDS diagnosis when their CD4 count falls below 200 and they develop something called an opportunistic infection. So when we talk about opportunistic infections, those are like pneumonia, bronchitis, cancer or other infections that come along with having a compromised immune system.

0:16:21 - Adele Scheiber

And you just said that the cd, what was, what was, cd4 count so is, is that your T cell count?

0:16:26 - Marnina Miller

So your CD4 counts are something that helps you remain healthy (Adele - Okay.) yeah, in your body. So your T cells and your CD4 counts are two totally different things.

0:16:38 - Adele Scheiber

Great, I'm going to put the definitions of those in the show notes. But basically it's part of your immune system, right? Okay, great, thank you for that.

0:16:52 - Antoinette Jones

They kind of are similar, like they help you fight infections exactly what Marnina said. But everybody has CD4 cells, right? And at the beginning when you asked this question, you was like "it was dumb for me not to assume that everybody knew what HIV was." That's not something that's dumb, honestly, because we want the world to get to a point where everybody knows exactly what HIV is, how it affects your body, how folks can be what. I would consider HIV possible, because anybody can acquire HIV and you know, it's not what it was in the 90s, where they put a label or a name on HIV, like a gay man's disease.

0:17:30 - Adele Scheiber

Yeah, or a grid. They used to call it grid.

0:17:33 - Antoinette Jones

Right and it's not like that anymore. So I think it's important to note exactly, we all have T cells, the difference between a normal or not a normal, but somebody who's not living with HIV body versus somebody who is, is it's just harder for us to fight off this infection, or, um, because we already have a diagnosis that is fighting against us. And also, like, when it comes to language, like Marnina said, in the early 80s, 90s, it wasn't - HIV, wasn't even the term that people were recognizing, it was just AIDS. You have AIDS. This is your diagnosis. Everybody just saw AIDS.

So oftentimes I also come from a testing and prevention space, so oftentimes you will hear folks talk about HIV as if it's AIDS. [Adele -Yes, yes] and it's time to combat that, like, “oh, you got AIDS” as if AIDS is the virus, when you have to have HIV in order to advance to AIDS. And it's not like you're just going to advance once you get an HIV diagnosis. No, like Marnina mentioned, you have to be very, very ill, sick, have comorbidities, not on treatment or HIV regimens to maintain your viral load to an undetectable standpoint in order for HIV to even advance to AIDS. And the good piece now, which a lot of people don't know, is that you can revert back to HIV after having an AIDS diagnosis.

0:19:10 - Adele Scheiber

Wow, Really?

0:19:11 - Antoinette Jones

Wow AIDS in the 80s and 90s, folks think that AIDS means that you're going to die, that it's permanently ill that you need to be in this section of the hospital. That's not what it is at all. With the right treatment and the right care, somebody can go from an AIDS diagnosis back to an HIV diagnosis and regaining their CD4 cells, as well as reducing their viral load, and still be healthy.

0:19:38 - Adele Scheiber

That is incredible to hear because literally everything you said was my mental model, right, and, and a lot of the people I know was like, okay, you know it, it always moves to AIDS. It might take years, it might take, it's degenerative, and then you die and alone in the

hospital, nobody even wants to touch you because you're, you know, like that's what cause, it's the movie show, right, and that's what, that's the stereotypes, and we'll talk about myth busting later. So I'm really relieved, you know, to hear that that's not the case. Can't wait to hear, hear more. And like the reason I thought you had to take a bunch of drugs, right, Marnina, is because that's what you see and that's what you hear. Used to be the case. But, sometimes medical research does actually advance. And, I guess while we're doing the one-on-one can, can somebody just go over really quick how does one contract HIV? Can we just cover that real quick?

0:20:30 - Antoinette Jones

So someone can contract HIV through five different modes of transmission. So you can have sex. So sexual transmission, mother to child transmission, how I got here? Um. Mother to child transmission, how I got here? Um. Anal sex, uh, vaginal sex, um is included in the sexual transmission. Um, someone who injects drugs is another way to acquire HIV. Um and um. Breast milk breast milk doesn't happen as often as it did in the past, um, but it is a mode of transmission and the reason I have to mention that it doesn't happen is because I'm somebody who breastfed my child last year and the guidelines around breastfeeding has been updated by NIH. So now it is recommended for parents to breastfeed or chestfeed their children if they're living with HIV, as long as they are under the care and supervision of a provider and undetectable.

0:21:33 - Adele Scheiber

Right, right, and we'll talk about that.

0:21:34 - Antoinette Jones

Marnina, Did I miss any as far as the transmission?

0:21:38 – Marnina Miller

No, you did great. Thank you for doing that.

0:21:40 - Antoinette Jones

(Adele - I appreciate that.) It's good to know that it's not kissing. Kissing is not a way. Uh, spit is not a way. It takes gallons and gallons and gallons of spit. People used to think urine was a way urine is not - you can urinate, it's fine. Um, toilet seats was one thing. Couldn't sit on the toilet seat after somebody - debunked it's a lie. Silverware or food utensils - it's a lie. You can eat after somebody. I ate after my mom my whole entire life.

0:22:14 - Adele Scheiber

So it's not casual contact. That's what I'm hearing casual contact.

0:22:16 - Antoinette Jones

Casual contact. If spit flies out my mouth and lands on your face, you'll be all right, you're fine.

0:22:24 - Adele Scheiber

That's comforting. Honestly, um and I do think a lot of people think that these things are, you know what I mean um,

0:22:30 - Antoinette Jones

And still to this day, like still to this day. I know Marnina could probably mention some of the comments that they receive just being what I would call an influencer on social media, but people will post comments with all these stigmas and myths that they believe to be true and be very loud and wrong in the process.

0:22:54 - Adele Scheiber

Yes, so thank you for giving us that, that preview into the myth busting. I'm busting myths for me over here, so back to you, Marnina, thank you. So you take one pill a day. What else do you do to treat and manage your HIV so that it stays HIV and it doesn't progress? What else do you do to treat and manage your HIV so that it stays HIV and it doesn't progress?

0:23:11 - Marnina Miller

So I think what I do every day is I live a normal life. I take one pill once a day and that's the only thing that separates my day from folks that are not living with HIV is that one pill once a day. I see my doctor every six months. I make sure that I am updated on my lab work. So she does all of my lab work every six months. I check in with her. I love my provider. She's a black woman who's been doing a lot of HIV research over the last 20 years and we have a really good relationship and so I just maintain my appointments. She maintains my viral load and we work hand in hand. She maintains my viral load and we work hand in hand. I see it more as a partnership because I am paying you and I tell folks you have the right to hire and fire your doctor as you please, and so.

0:24:02 - Adele Scheiber

I tell people that every day on this podcast. That's great, that's, that's truly incredible. That's a real aha moment for me, and I'm sure it will be for a lot of listeners. So, Antoinette, so your story is a little different. You were born with HIV. It was contracted from your mother, so can you talk to me about what maintaining your health has looked like throughout your life?

0:24:22 - Antoinette Jones

Yes, so actually in here in Marnina's we do have some similarities, Marnina.

The only difference is the fact that I was born with HIV and have been living with this sister, cousin, friend my whole life and thriving, honestly. But it took a while before I got to this point. So treatment when I was in my adolescence was very, I would say, helpful because I had the support of my mom, so it made it easier, um, but that didn't um, that didn't separate the the impact of HIV on my mental health and on my um, my overall like processing of life and who I was and you know just my self-worth. But having the support of my mom to take me to doctors, to pediatric care, and pediatric care is very different than adult care. You actually - you have providers who are like holding your hand, you get a lollipop for being undetectable, you get stickers, you get presents because they love, we love the children. So, it's a little different. They're a little more gentle.

Some children at that age don't know of their HIV diagnosis yet, so you have to talk to them a certain way or talk around them to their parents. And then some do and, um, you are very limited about the information that you share because sometimes parents are still in the

space, like I didn't have an appointment with my provider without my mom being present. So wanting to ask questions around sex, and especially at the age of 14, like, oh, I want to have sex, I'm thinking about it, I want to talk about pleasure, I want to talk about all of- (Adele - how to tell people, what they might say.)

Yeah how to disclose.

Um, I really wasn't able to have those uh one-on-one conversations with my provider without my mom being there, because, she was always in the room because I'm a minor. So, once I got 18, my mom was like you are 18 now, so I'm giving you your diagnosis, like I can't hold your hand anymore, and it was like it was a good time. But it was a bad time because I had just transitioned into adult care and, like I said, adult care is not like pediatric care. So, you have to take care of the responsibilities of scheduling your own appointment, picking up your own medications, actually uplifting and advocating for yourself in a patient-provider setting, asking questions, reading your own results or like bringing it up to your provider.

Sometimes it's real quick, you in and out, and you're like wait, I had more to say, I had you know, there's still, or I forgot what the five things that I knew I wanted to ask you before this appointment, and now we in and I forgot. So, all of those things. But for me.

0:27:20 - Adele Scheiber

And that's hard. That's hard even when you're not living with a chronic illness like that, that transition that you just described. Like I didn't go to the dentist for four years, you know, because I didn't want to call and deal with that like I can't even imagine my life depending on it and having to deal with that. So good for you, man, 18 years Right.

0:27:34 – Antoinette Jones

But it was challenging. It was like, It was like a surprise for me because I'm like, I don't have my mom here and that's when I actually- But that's when I was actually able to put a name to mental health and what depression was, what anxiety was, um, how I was like harboring all these feelings about HIV and myself. Um, because I hated HIV like I couldn't stand it for a very long time, and that, overall, impacted how I took my medicine, if I took my medicine or not. Um, how long I maintain that undetectable viral load. Um, and these are the experiences of not just myself, but so many other dandelions in the community. And also,

like medication fatigue is a big thing in our community. We get tired of taking the medicine. From 11 years to 29 years. It could be draining, and I had to learn a lot in that care and treatment.

But to Marnina's point, you mentioned community, like how you found community and that was like your saving grace. That's literally what happened to me. I was not doing well in my HIV diagnosis, I hated HIV and then I found community when I was 24. I met my first person who was born with HIV. I never met anybody before I met another Black woman who was living with HIV for the exact amount of years I was, but her story was different. And I found an organization in Atlanta that was centered around women living with HIV. So, it was like once I found that community I heard these different stories, their experiences. I felt seen, I felt heard, I felt like I could do this, like my life was worth living. But I went from taking seven or eight pills, liquid medication before that, it was disgusting. Just trickling down to eventually four pills, to eventually three pills, and then now to a one pill once a day.

0:29:41 - Adele Scheiber

So you've really gone through. You've gone through the whole journey. I mean [Antoinette - oh yes] the 29 years of HIV research has been written on your body. That's crazy.

0:29:50 – Antoinette Jones

I tell them all the time, we are the research, yeah we are the reason that it has advanced this far because

0:29:54 - Adele Scheiber

And I hope we all yeah, I hope we figure out video for this episode, y'all, because I mean you guys are just, you radiate such confidence and such resilience and like beauty and as you tell your stories, and I mean way to go way to stick with it, you know, because I don't know if I could be taken four pills that's impressive.

0:30:14 - Antoinette Jones

It was gross and, honestly, the liquid medicine is so much more worse than the pills and my mom had the most challenges with me. Like just take it, please, put it in applesauce,

put it in milk, put it in all types of stuff, just so I take this medicine. And I was just like so I had a ton of challenges.

0:30:34 - Adele Scheiber

God, That's fascinating Because you know, Marnina, you were diagnosed as an adult. I, you know, kids you know they're, the long-term thinking, the consequences, the you know. I think it's interesting that you found that community and you started to accept your diagnosis when you were around the age of 24, which you know. There's that popular wisdom that your brain is like done, maturing at that age. You know what I mean, and it's, it's, you're ready to you know you're faced these adult problems and it's unfortunate that you had to deal with them literally since you were born, but I'm glad that you're here with us today to share that experience, because you're going to help dandelions everywhere. I was so excited for this interview and then, okay, so you've mentioned undetectable viral load, so now we're on my favorite, the myth busting question. But also, before we get to, what myths do you guys want to bust about HIV right now? What does this whole undetectable viral load actually mean and what does U equals U mean?

0:31:32 - Marnina Miller

I'm so glad you asked that question, because when you asked me how do I maintain my health and take care of myself? One thing that folks don't like to talk about is the fact that folks living with HIV are having sex. And baby, we're having sex too.

0:31:48 - Adele Scheiber

So this is new right the U equals U like like. This is a new discovery. Isn't that right? Didn't the CDC just acknowledge this?

0:31:55 - Marnina Miller

So the CDC may have just acknowledged it, but people have been knowing about undetectable, equally untransmittable, for a very long time.

0:32:03 - Antoinette Jones

And that's why I said we are the research, for at least 10 plus years, we've really learned to speak on it.

0:32:11 - Marnina Miller

No, you're good answer there. I would love for you to also talk about this too. Um, actually Bruce Richmond, an HIV activist. Came up with the campaign for U equals U because he wanted more marginalized communities to know about the science behind U equals U, because our doctors weren't telling us about this science, and what U equals U really means is undetectable equals untransmittable. Just like Antoinette was talking about, about these studies around the bodies of folks living with HIV, there were three large studies done on the sexual transmission of HIV where there were thousands of zero-discordant couples, meaning one partner is living with HIV and the other partner is not. There was not a single case of HIV transmissions from someone who was virally suppressed to their HIV negative partner, and so this means that folks were having anal, vaginal sex, and no one contracted.

This was thousands of couples, and so Bruce Richmond said, "I want more folks to know about this science. I want more folks in my community to know that undetectable equals untransmittable." And so now we have the language of U equals U, but it took the CDC years to sign on to this. It took health departments years to sign on to this because they didn't think we could "responsibly handle" this type of information and we know that the HIV epidemic is a racial justice issue. It disproportionately impacts black and brown bodies. Because of the lack of dissemination of information, this information has been out for decades. Our folks living in other, what they like to call third world countries, like spaces in other marginalized spaces, which to me their first world countries because they've been knowing this information for years.

0:34:12 - Adele Scheiber

Yeah, we like to say economically disadvantaged at this point, because it's really just about the money and the marketing of those countries.

0:34:16 - Marnina Miller

Yeah, just like Antoinette talked about breastfeeding and chest feeding. Folks our African brothers and sisters have been breastfeeding and chest feeding for decades without HIV

transmission. The CDC is just now changing the guidelines, which goes back to like, this issue around body autonomy of people living with HIV and the erasure that happens when we receive our HIV diagnosis.

0:34:46 - Adele Scheiber

That's so real, gosh. Well, I have a question, okay, so basically, what I understand U equals U to mean, as a person from the outside who just heard you talk about it and has heard about, it is if your viral load is low enough. So, if you're essentially in remission, right? I don't know if I'm using that right, you can have sex with somebody who does not have HIV and it will not transfer to them.

0:35:13 - Marnina Miller

You have to say if you have an undetectable viral load you cannot transmit to someone else. So if my viral load is undetectable, which means I have 20 copies or less in my body, then I cannot transmit the HIV virus.

0:35:24 - Adele Scheiber

Okay, and so anybody who contracts HIV can. So, this is a goal you can get to undetectable, essentially, with the right treatment. [Marnina – Yes]. I guess my question is, you know, the question I would have as somebody without HIV is what if that changes? What if your viral load spikes? Do you know what I mean? Like? Isn't that a risk? This is a question I know lots of people have.

0:35:48 - Marnina Miller

So, yes, I'm passing on to Antoinette to answer this one.

0:35:52 - Antoinette Jones

So, Marnina just shared, like a specific number, that she said 20, right, and that number varies in different states. They can't land on a number, on like a national number where it's like, oh, everybody needs to be under 20.

0:36:09 - Adele Scheiber

We can't agree on anything.

0:36:11 - Antoinette Jones

Undetectable, Right. So, in Georgia it's 50. When I was pregnant it was 60 or under 40. In some states it's 100. Then you're considered undetectable, and now I just heard at a research conference that is actually a thousand. Like there's. No, yeah, there's, there's not a specific. I want to say there's not a specific number. It's great to be at least under 50. It's even better to be under 20. But if there's a spike at all, I feel like the risk and the chances are still very low to transmit.

The folks who were in that study that Marnina mentioned, all undetectable, right, because at first the undetectable viral load was under 200. So, it was especially at that time everybody was under 200 at least. [Adele – Wow] Yeah, so it varies, it's different in different states. Where you go is different, but-

0:37:11 - Adele Scheiber

When you peel back that onion. Isn't it funny how imprecise and on a spectrum, everything is right, like what I. What I think is so important about sharing the U equals U message is you know it reduces stigma? Right, I would hope anyway. I mean, has that been your experience?

0:37:30 - Antoinette Jones

Yeah, I would say so. I would say anyway. I mean, has that been your experience? Yeah, I would say so. I would say it has, especially around like having a partner and being able to voice that. There is a. There's a study, there's findings that that you can look back on, and it says that I'm unable to transmit. There's research around this, you know. So it's good to have that backup.

Even with my journey around breast and chest feeding like it was a it was a fight, because I was I was probably one of the first people um, along with a few other advocates, to make this decision, to go against the grain and be like nope, we're breastfeeding our babies. Can't tell us, no, we're going to those doctors. And the push was our, our advocacy stance was the fact that, well, we're undetectable and that's what y'all told us to do. Y'all told us to get undetectable and now we are. So you shouldn't be combative with me about making this decision, because if I can't transmit while having sex, then I can't transmit while having sex, then I can't transmit it while giving or breastfeeding my baby.

0:38:33 - Adele Scheiber

That is exactly... I'm so happy that there are advocates like you out there who are, who are calling out the talking on both sides of your mouth, kind of paternalism.

0:38:53 – Antoinette Jones

You gotta throw the research back in their face like, oh, remember this uh, great research that you all did. Um, here is it back in your face. Because, yeah, you can't tell us to do one thing, and then say another .

0:39:01 - Adele Scheiber

All right, because what's the point of doing that thing, then what does that word mean then? What does undetectable mean? We have to. I think this is something, and it's something the NWHN is really we push for, like it's great that we're doing studies and that we're doing all this, but we need to be able to translate that into actionable things for people right, into actionable and consistent and replicable recommendations for people that are actually going to make sense, and so it sounds like organizations like you were really working towards that and getting that consistency, which is so important in this space. What other myths? So here's the rapid fire myth busting. What myths do you want to bust right now? Go popcorn style.

0:39:36 - Marnina Miller

That is a hard one, oh, I guess. So Black women currently make up 60% of those that are of women that are living with HIV. So, of the percentage of women, although we only make up 7% of cisgender women, we make up 60% of those that are living with HIV. Also, black transgender women make up about 60 to 70% of trans folks that are living with HIV. So HIV is a racial justice issue. It's also a gender justice issue.

Globally, women make up over 50% of those that are living with HIV. So, even internationally, this is still an epidemic. It's a pandemic, still. Folks think that HIV no longer is an issue within the United States or abroad, but it definitely still is, and we know that HIV is a symptom of a community that does not have everything it needs. So, as I'm talking about, like stats and statistics, we have to know that it is not because Black and Brown women are doing sex any different or that we have some sort of issue. It's the fact that this is an economic justice issue, it's a racial justice issue and it comes along with lack of access to housing, healthcare, resources. It's a laundry list of issues and it's just a symptom of a community that does not have what it needs to live and thrive.

0:41:12 - Adele Scheiber

Yeah, well, and since you brought that up, can you maybe share your thoughts on what are those deficiencies that might, what are those social determinants of health that might raise your risk of contracting HIV?

0:41:24 - Marnina Miller

So we know that folks that are living at or below the poverty line are more susceptible to receiving an HIV diagnosis due to lack of access to health care. We also know that in communities of color, there is a high incidence of transphobia. There's also issues around racism and queer phobia. You also have misogynoir, which is the hatred, or the ingrate hatred, of Black women, so Black women not receiving the resources that they definitely need, and all of those issues just really make up a perfect storm of inequity that definitely impact communities of color and LGBTQ folks as well.

0:42:12 - Adele Scheiber

Yeah, yeah, thank you for that. I think people forget that this doesn't happen in a vacuum. This disease today is not in a vacuum, just like it wasn't in the 80s and 90s.

0:42:22 - Marnina Miller

Oh, another thing to do before we go on. I would love to add that the lack of access to preventative medication is real too. Although black and brown folks are most impacted by the epidemic, when it comes to prevention and prevention services, uh, we are lacking in that area. We don't have access to PrEP, which is-

0:42:45 - Adele Scheiber

I was just I was just going to ask about PrEP. Yeah, so PrEP is that was like I think it was on the mark. Can you tell us a little bit about PrEP? Can you go into that? And it's probably expensive, right Is why we don't have the access to it.

0:42:55 - Marnina Miller

Yes, PrEP is extremely expensive. PrEP is pre-exposure prophylaxis and there's also a medicine called PEP which is post-exposure prophylaxis. You would take PrEP before you had sex with someone living with HIV so that you wouldn't transmit, or if you didn't know their HIV diagnosis. So let's just say you are having fun and you want to make sure you are protecting yourself. It's another tool in your toolbox that you can have. Post-exposure prophylaxis is a pill that you take after the sex, between 72 hours after possible exposure to someone who was living with HIV.

0:43:32 - Adele Scheiber

I didn't even know there was that. That's incredible and so, but like, does insurance cover these things? Does Medicaid cover these things, like any you know? Is that? Talk to me about the access barriers there to preventative care.

0:43:46 - Marnina Miller

So that goes back into the social determinants of health. In the South, there isn't a lot of Medicaid expansion in most Southern states. I know the person that lives in Texas. There is no Medicaid expansion here, so if you are trying to access that, that is something that won't be able to be accessed. Currently. There is an injectable that you can also take for PrEP

um, and it's a once a month or bi-monthly um shot that the doctor gives you in office that you can take as well, instead of a once daily pill. Uh, but they are both quite expensive. They are. They can be covered by insurance, but it depends on if your insurance carrier allows you to be able to use it. Um, some of them have said that they don't want to cover uh medicines like PrEP, so some insurances don't cover PrEP medications currently in -

0:44:42 - Adele Scheiber

That's Wild. We've been trying to end this thing since the 80s and we have the tools to do it and we're just not. We're just going "no thanks," Like, what?

0:44:53 - Marnina Miller

Like in the Texas formulary. So there's this list of medication that Ryan White covers currently in the state of Texas. So, there's this um list of medication that Ryan White covers currently in the state of Texas. Currently there, the medicine that's in an injectable for people living with HIV is not on that list of medications that's approved by the state. So, if you want to have an injectable and you're on additional assistance like Ryan White Care, you don't have access to that. So, these are the additional layers that impact the ways in which folks are able to access treatment and care.

0:45:28 - Adele Scheiber

Yeah, wow, it really well we're. We're really bad at prevention in general. We love to just defer, but that's, that's egregious, my goodness. All right, so let me think in today's day and age, if you follow the treatment regimen, is there any reason to assume that your life expectancy will be shortened by this disease?

0:45:46 - Marnina Miller

We're both looking like oh, should we call in. So, I do want to say this one statistic too.

I know I'm saying a lot of stats, but [Adele - no, we love that] and what I want folks to know is that statistics without the full story is violence, and so I hate not saying the full story of folks' experiences when I'm naming out these numbers. Black women between the ages of 18 to 44 are the only demographic in this country whose top 10 leading cause of death is still an AIDS diagnosis, and so Antoinette and I have lost several folks, and I know

Antoinette has lost way more than I have, but we have definitely lost advocates, friends, sisters, even folks who are doing this very work that we do, due to lack of access to care, mental health, and a wide array of things that still impact folks living with HIV. But I would love for Antoinette to talk about this a little more too.

0:46:56 - Antoinette Jones

Oh, Marnina. Long life. When I think about a long life, I have to question what that looks like. Because, like you said, medications have come a long way, research has improved, but, from my standpoint, people are still dying. We are still losing dandelions, like at a quicker rate from other comorbidities, um, in addition to HIV. So, um, we lost somebody who was in our community to breast cancer last year and they were 31 years old, and we continue to question, how could, how could the HIV field fail this young woman? Um, and nationally, we, nationally, we failed this young woman because you look at the recommendations for screening somebody with breast cancer or potential breast cancer, the age is 45, 55. And, um, she doesn't fit into that criteria. So why would anybody think to screen her for breast cancer? Without realizing that people who have lived with HIV for a lifetime or a long time, should be screened for a lot of these different comorbidities and issues a lot sooner than the rest of the population.

Or we think about our mental health, just the overall acceptance of living with HIV. So, yeah, I may be undetectable, I may have gotten my, I got my care team, I got my support, but inside I'm hurting, inside I'm tired. I don't want to live anymore. These are the. I don't want to say the issues, but the experiences of a lot of our community.

People are burnt out, people are tired, people want to rest, people are, um, ashamed or have been treated unfairly, or by their families, yeah. So sometimes something inside somebody dies long before they actually transition off this earth, um, and it could be as soon as they receive an HIV diagnosis and they just don't you know. There's just something. So sometimes, yes, it is the age that kills us, right, but sometimes it's but sometimes it's other- These other social determinants that transition us off this earth.

0:49:31 - Adele Scheiber

I think you speak to something, gosh. Every day I'm reminded I have to check my privilege at the door like a coat check, because I fully expect it, because I've been talking to a lot of well-to-do white gay men about HIV and AIDS. Like that's the people that I know, you know what I mean. And they're like, no, we're going to collect retirement, don't even worry about us, we'll be fine. But it's like these social determinants and these health disparities that Black women are facing and that women face.

It's a very different story, it's a very different feeling, right? And I mean I had no idea about the top 10 cause of death. I mean that's, that's outrageous. I mean that's in a world where one population with this disease feels very optimistic and can be drawing their social security and is not afraid of that imminent death. And we're this, I mean we're in the same country. We have access to, you know, to the same things. I mean that's that really speaks. That speaks a lot. So I would say the myth I was going for was no, this wouldn't shorten your life. But really the myth is that everybody has access to the same sort of time and attention and care. That's the real myth, is what I'm hearing from that answer. So thank you for that. Thank you for that amazing answer.

0:50:47 - Marnina Miller

We haven't even touched on, like the violence that's perpetuated against women living with HIV. PWN created a day, which is October the 23rd, which is a day of action to end violence against women living with HIV, because what we know now, and when I say women, I mean women in all of our diversity, all femmes, so trans women, non-binary folks that are femmes, are included in my definition, but 70 % of us will experience intimate partner violence within our lifetime, which is crazy within itself.

0:51:25 - Adele Scheiber

That's really high, isn't it? Like what's? What's the baseline? I don't know the baseline off the top of my head, Like what's the average or whatever.

0:51:33 - Marnina Miller

So, what's really causing it is stigma, discrimination, someone telling your diagnosis and them perpetuating violence against you, or using that as a way to control your body or

control your fertility or control your life. That has happened to so many folks that are living with HIV, especially women.

0:52:03 - Adele Scheiber

So this leads really well into my next question, which is, if both of you could like wave a magic wand, what would be different about HIV policy access? Just the state of HIV in the US?

0:52:16 - Marnina Miller

If I could wave a magic wand, I would ensure that everyone, regardless of their socioeconomic status, race or gender, would have equal access to HIV treatment, care and preventative services. I would take away all stigma, as a matter of fact, I would just take away HIV in totality.

0:52:38 - Adele Scheiber

Fair. Which is possible, hello!

0:52:43 - Marnina Miller

I truly believe that this includes access to affordable medications, mental health services and really like community resources to make sure that we all are living well. And I will also add in what Antoinette says a lot is radical rest. And I will also add in what Antoinette says a lot is radical rest. When I first heard Antoinette say that, I was like, oh my God, I love that.

0:53:07 - Adele Scheiber

What is that? Tell me more, because I'm going to start using that.

0:53:16 – Antoinette Jones

It's just the ability to rest without rest, while feeling unapologetic about your rest, like rest to the magnitude that you choose to rest Just to do it without a care. Sometimes we take

rest in this world and we feel so guilty about it. But it's just releasing all of that and being able to rest to know that it's a care for your body. And rest looks different for everybody. I may want to sleep till noon, I may want to eat all day, I may want to party like. Rest is different and it's radical, so it's completely up to you you own it.

0:53:47 - Adele Scheiber

It's radical in this society, in this economy and this ode to capitalism right.

0:54:01 – Antoinette Jones

And it's going against capitalism, like going against the status norm of what you're supposed to do (Adele – yeah.) it's a middle finger.

0:54:01 - Adele Scheiber

Radical rest. Well, and you speak to. You know people with chronic conditions are fighting this battle constantly, this like battle to take care of your bodies in a way that maybe people who don't have chronic illness aren't. So rest is medically necessary. I mean, it is for everybody, but it's like doubly so for folks living with a chronic illness. So I love, I love radical rest. And, Antoinette, the next question is for you. So you're a field organizer with PWN. What are you organizing about? What are you getting people to do?

0:54:33 - Antoinette Jones

I'm organizing about so much, including radical rest, including the healing and the the healing and gender justice of our people, the the resilience and the healing and gender justice of our people, the resilience and restoration is a form of organizing. I'm organizing around, making sure that our members are aware of policy and legislation moving around them that will directly impact them in their local areas, giving folks the tools, along with the rest of the PWN national staff, that they need in order to advocate for their own needs, in order to speak up about injustices, in order to, like, just do the work on the ground, so that they are in those decision-making tables, so that they have decision-making power. So a lot of the work that I do is empowering others with tools that they need, whatever they need. Honestly, like I said, we're member-led.

Even though me and Marnina are members, we're staff, so sometimes we silence our own voices so that our members can be in a position to speak up to share what their needs are, and to demand what they want. So that's a lot. I know it's a lot, but we do a lot, you know, for the better good of our community, and encompassed in that is making sure that our community is well, making sure that they're healthy and they're living long, dignified lives, make sure that they feel good, that they're loved, that they have community around them and they know that PWN is here, like we are here to support them and whatever it is that they need and wherever they are at on the spectrum of life and advocacy and their journey living with HIV.

0:56:22 - Adele Scheiber

That is a lot. That's a huge portfolio. That's really broad. What so? Just if you, what are some of the biggest, is there anything federal you guys are working on that that maybe our members could help out with or our listeners might want to know about? Or even statewide, like what are like one or two things, like one or two big pushes you're working on right now?

0:56:42 - Marnina Miller

So we're actually doing a lot of work around integrated voter engagement. (Adele -Okay, good, good!) A lot of issue-based organizing. Currently, within three different states, we are doing integrated voter engagement, so in Texas, in Pennsylvania and also Colorado. We have members in almost every state in the United States and so we have members at large. We have members that are in chapters and so the ways in which folks can get engaged with the work that we're doing. Follow us on social media at PWN, underscore USA, to get more involved in the work we do. We do have, like petitions that we have that we're rolling out around harm reduction. We have petitions that we're also talking about with DAs and in different states and so get to know more of the work we're doing. We do a lot of policy, federal work.

(Adele -Okay, good, good!) Currently, we're doing a lot of work around the quality of life of people living with HIV through the US People Living with HIV Caucus, and so we also attend a lot of conferences. You can also donate to the work that we're doing, because most of our funding goes straight to our members and our member-led organizing.

0:57:59 - Adele Scheiber

Yeah, yeah, no, that's awesome. We will link to all of the things in our show notes, anything you want us to link to, but definitely at least your website and your social media for sure. All right, friends, is there anything else at all? And you can plug literally anything that you want our listeners to know before we end today.

0:58:19 - Marnina Miller

I think I just wanted to add a little bit more about our mission. The mission of PWN is to prepare and involve women living with HIV, including our transgender folks, at all levels of policymaking to improve women's lives. So we do that through really four strategic ways by combating HIV stigma, training and supporting women living with HIV, creating and sharing tools for women and HIV advocates, and also mobilizing and engaging them in campaigns to change policy. So we have a policy fellowship. We also have something called the Health- not Prisons Collective, which is a collective of organizations that are working to end all forms of criminalization and abolitionism work. So one of the main policy works that we're currently doing is trying to end HIV criminalization in the United States. Every state has its own HIV-specific criminalization laws. Some of them are repealed. Some of them may not be on the books anymore.

0:59:24 - Adele Scheiber

What do you mean by HIV criminalization. Can you talk about what that means?

0:59:27 - Marnina Miller

Yeah, so HIV criminalization are laws that were set up during the time of the early days of the epidemic. The United States government said in order for us to give each state access to care and treatment or money and funding to be able to combat HIV in their particular states, there needed to be an HIV criminalization law on the books. So each state has its own state specific laws or statutes. Currently in Texas there is no HIV specific law. However, there is something called sentencing enhancement and currently in Texas my body is seen as a deadly weapon. So if I have sex with someone and I don't disclose my HIV status, I could potentially be imprisoned for it. And let's just say, if I did disclose my status and that person lies and says that I didn't disclose my status, I could still be incarcerated.

And who would listen? You know judges are not impartial. They are probably going to listen to the person that is not living with HIV. So each state is different, each state -

1:00:45 - Adele Scheiber

Interesting, So so you're literally talking about the like, the disclosure, the laws related to disclosure and liability related to disclosure. Okay, thank you for explaining. I didn't realize that. Yeah, because you hear those stories and it's that's interesting, because so many times those stories are like, oh, he should have told you. It's a lot of time, like you know, women are sharing a tiktok and be like the law will get him, and it sounds like these unintended consequences of laws like that or maybe they were intended, who knows right are actually just further stigmatizing and maybe even unjustly right. Because, like, what if you did disclose, it's not like you wrote that in a contract, right.

1:01:19 - Marnina Miller

And it's not based in science. Right, it's not based in science because the laws are still from the 90s and so that's what we're trying to combat is the lack of science. With these antiquated laws and also the, which is where the CDC is literally taking our bodily fluids without our permission. There's no way to opt in or to opt out from the. (Adele -They're Henrietta Lacks-ing you?) Yes, basically, yes, yes. (Adele - Really, I thought we were done with that.) It's so serious, like it's so many policy issues that are floating in my head. What are y'all working on? So there's a lot, including all of the other intersectional things around harm reduction, transphobia, the erasure of the body, autonomy of children, of trans children, like the anti-Blackness that's come like. It is so much that's intersecting people living with HIV that our policy team is exhausted.

1:02:29 - Adele Scheiber

I bet Well, yeah, well, we. This will not be our last conversation. I'm just going to say that right now, so don't worry, we will talk about because this is truly I mean it's so under discussed. I mean, I work for a women's health organization, right, and this is some of the first times that you know I'm hearing about these things. I'm just going to use an I statement there. Maybe my colleagues knew more, but you know, thank you so much for sharing. What else? Anything else at all.

1:02:54 – Antoinette Jones

I would like to answer the magic wand question. So if I had, a magic wand?

(Adele - I'm sorry.) I think no, because it's like when my name is the HIV and just period HIV, I was like, oh, that's definitely something that just needs to go. But if I had a magic wand, it will be for around body autonomy and just giving access, giving the rights back to the people who are of lived experience and allow us to make all the decisions necessary for our own bodies. Because we are living with HIV. Oftentimes, policymakers, doctors and providers and, you know, folks in power don't believe that we can make decisions for ourselves, healthy decisions, like taking one pill once a day and becoming undetectable. So I just think that we deserve our power, like we are more than capable of handling our own bodies at all times. So that's actually what I believe, folks with that, you know, people living with HIV. There's so much more beyond our HIV diagnosis. Um, there's uh. PWN is just um, an organization that uplifts that fact, along with the rights, around our policies and legislation. So, knowing that we are powerful, like I said, we are strong, we are women, we are resilient, um, and we are intersectional, intergenerational. So there's just so much more about us beyond our HIV diagnosis.

1:04:32 - Adele Scheiber

Amen, Thank you. Thank you so much. It has been a real privilege and truly I think I've learned the most from this interview and all 46 so far that I've done so. Thank you, guys, so much.

1:04:47 - Adele Scheiber

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