AKeem fills us in on HIV/AIDS 101

CREATIVE WORK
Contributors from the HIV/AIDS community share their work.

CEDRICK TAYLOR
Read about Cedrick’s experience living with HIV and his work in the community.
"There is no such thing as a single-issue struggle because we do not live single-issue lives."
Audre Lorde
When I attended schools in my earlier years, I didn't have the opportunity to learn a lot about sexual and reproductive health. Instead of learning medical accurate information, I received the information from my peers. As an adult, parent and caregiver, I have grown to become more passionate to share information I wish I had, to our younger generation. The cliche, health is wealth means a lot to me. I am grateful for my Art of Me team and community of supporters to be able to provide this information for the community I grew up in and believe in serving. It is never too early to start talking to our little ones about their bodies. The little ones, become middle schoolers, teens and adults who are living with the choices they've made. If I could place a price tag on this magazine I would label it, priceless. It is invaluable to give our communities medical accurate information. I thank you for giving us your time by checking out our magazine and all we ask is that you share this information with at least two others in your community. There is power in community.

Stephanie Wahome
EXECUTIVE DIRECTOR
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CLEVELAND, OHIO
16781 CHAGRIN BLVD, STE. 184
SHAKER HEIGHTS, OH 44120

BROOKLYN, NEW YORK
68 3RD CW#60
BROOKLYN, NY 11231

WWW.ELITERUNNER.COM
There are many ways to prevent HIV:
- Getting regularly tested for HIV if you are sexually active
- Taking PrEP or PEP (tablets which prevent HIV either before or just after you have been exposed to it)
- Using condoms
- Never sharing needles
- Taking your medication if you are living with HIV
My time with the HIV/AIDS community started off with me feeling very nervous. I was worried because I felt several worlds away from that world. When asked to reach out to people from that community ranging from activists and health providers to positive individuals, I felt ill equipped. I began to do research so that I could sound as politically correct as possible because my biggest fear was that I would offend someone. None of that happened. Thankfully, my desire to know and understand was enough. I had to realize that the questions I was asking, however awkward or strange they felt to me, were questions that so many people had and the answer I received would not only solve my desire to understand but also bring understanding to other communities without this information. When I realized that it wasn’t just an interview or just a job assignment but a chance to change at-risk communities, I began to relax a lot more and be okay with what I didn’t know.

Looking back I’m very thankful to everyone who took the time to talk to me about the flourishing scientific realm of HIV/AIDS, the social setbacks and progress, and the handing down an invitation to allyship through information and testimony. However, I want people to realize you don’t need an invitation. The fight against HIV/AIDS belongs to us all. It involves not one specific community, but all communities.

Chanda Bynum is from Cleveland, Ohio, and has been writing short stories since the age of ten. Introduced to spoken word and playwriting in high school, she has always felt compelled to tell her personal story and the stories of other people around her. Chanda desires to not only direct movies but also to write and produce a television series on a popular television network. Currently, she is interested in serving others by telling their personal stories through unique perspectives and visuals to inspire diverse readership and viewership and bring people from all different backgrounds together.

Chanda coordinates the "Power & Community" Podcast and served as the liason to the folks interviewed in this publication.
CHANDA: How and why did you get started in sexual health and HIV/AIDS prevention?

KATHRYN: I’m originally from New York. I lived in New York from ’85 - 95’-ish. I lived in the lower east village and had a lot of friends who were HIV positive and at that point the only medication available was ACT, which made you incredibly sick. You had to take it 4-5 times a day.

"So to have a medication that I can hand somebody and say: "this will keep you from getting HIV", that’s incredible! That’s like a modern medical miracle."

It worked...mostly. I got involved in sexual health, got my Masters in nurse partitioning and was lucky enough to get a job at Metro where I specialize in sexually transmitted infections. And then when PrEP became available, to me that was: “oh my God we have a medication that can prevent HIV.” Coming from New York, all of those years...there are a lot of people who aren’t a part of my life anymore.
So to have a medication that I can hand somebody and say: “this will keep you from getting HIV”, that’s incredible! That’s like a modern medical miracle.

CHANDA: What I’m hearing is that this isn’t just a career for you but this is very close to your heart. You’ve known people, have grown up with people and have lost people. It’s really refreshing because I feel like a lot of times people just take jobs these days. (Laughs) Often we don’t run into people who feel connected to their jobs. Even some medical professionals can be more technical and not emotional— I know that we’re gonna get into some really juicy discussions today.

KATHRYN: Thank you for the compliment on my age. I was actually on my own in Manhattan in my own apartment and in my twenties. It was a very informative time, even more so than growing up in that community.

“HIV preventative care is a cluster of care that involves the HIV patient and the non-HIV patient. It’s a way to keep people who don’t have HIV from getting HIV.”

CHANDA: New York is very busy. I’ve been there about three times and at one point thought that I would live there because I am a writer and writer’s thrive there. But every time I went it was very overwhelming. Wait, before we get into the nitty gritty can you talk to us about how you got acclimated there? As far as New York being busy, being cramped, you know the hustle and bustle of it?

KATHRYN: I just love it! I’m an extrovert and I grew up outside of Long Island, outside of New York. I moved into New York after college. It was never a matter of acclimation. for me the acclimation happened when I came to Cleveland because my first apartment in Cleveland had doors coming out of the studio and it had a little balcony thing--it wasn’t a fire escape, it was an actual balcony.

CHANDA: Yeah, Cleveland’s definitely different than New York. Sometimes when I got to downtown Cleveland I laugh because I don’t see it as a “downtown”. There are a lot of great restaurants and things but there aren’t a lot of people. There’s a lot of space to walk. There’s a lot of breathing room. It’s not busy like maybe downtown Chicago or downtown New York would be. So I can see what you mean about the pace changing severely for you. Earlier you talked about the advancement of HIV/AIDS prevention you mentioned “PrEP”. Before you get into what PrEP is, can you tell us what HIV preventative care is?

KATHRYN: HIV preventative care is a cluster of care that involves the HIV patient and the non-HIV patient. It’s a way to keep people who don’t have HIV from getting HIV. But it’s not solely on one partner or the other. It works best when it’s a combined effort.

CHANDA: When talking about HIV preventative drugs, can you give us a list of drugs and how they prevent the transmission of HIV?

KATHRYN: So currently on the market there are two approved drugs right now. TRUVADA and DESCovy is the newer one and a littler pill. They work by creating protective walls around the cells of the immune system that are open to HIV coming into them.

CHANDA: Is this what stops the HIV from multiplying itself and spreading into the body?
KATHRYN: Right. So when somebody who’s not infected with HIV comes into contact with someone who is infected with HIV and the HIV virus goes from one person to the other it finds this immune cell and it hooks into it. Then it uses that cell to send out many, many copies of itself. So PrEP, (Pre-Exposure Prophylaxis for HIV) creates these protective barriers [forms squares with her hands] it’s kind of like building a mote along a castle wall but around your immune cells to prevent HIV from getting to them. Prep works very similar to some kinds of vaccines as it prevents the virus from having somewhere to go in your body.

CHANDA: Is PEP the same as PrEP?

KATHRYN: No. So PrEP is pre-exposure and PEP is post-exposure or after you’ve had sexual intercourse. PrEP is one medication. PEP is two medications and usually used because of a broken condom, sexual assault, or whatever reason a person has in which they haven’t taken other protective measures against HIV.

CHANDA: So if you’ve had sexual intercourse with someone, consensual or non-consensual, this is what you would take to get in front of being infected?

KATHRYN: Correct. It’s two medications and by taking the two medications as soon as possible after you’ve had the exposure, you can kind of, hopefully, stop it. Have you heard of emergency contraception? It’s a pill that you can take after sexual intercourse to prevent pregnancy. PEP is a pill that you can take after intercourse to prevent HIV.

CHANDA: I was literally gonna ask if it’s like a plan B pill but I didn’t know if that was gonna be weird to say! (Laughs)

KATHRYN: Nope! I always talk about PEP and PrEP in relation to birth control because they’re very similar. Not in what they do to the body but in how society thinks about them.

CHANDA: Good to know. How long do you have between intercourse and infection with PEP? Is it in the 72 hour range?

KATHRYN: You can take it as soon as you’re done having sex if you can find someone to prescribe it that quickly. After 72 hours it probably won’t work. And the FDA has only approved it for up to 72 hours after the act of intercourse. There are providers who will provide it up to five days after intercourse with the understanding that it probably won’t work. But we don’t have that many other options. So some providers are willing to do that.

"PrEP is pre-exposure and PEP is post-exposure or after you’ve had sexual intercourse."

CHANDA: So while we’re on the topic of prescription, how does one get PEP? How does one get PrEP?

KATHRYN: So you have to see a provider. A lot of the ERs, especially in the Cleveland area, I don’t know if it’s in the New York area as well, but you can go to the ER and tell them you’ve had a condom break and they will actually hand you the PEP, which is amazing. It’s taken us many years to get to that point and it’s pretty exciting. Alternately there are companies online, there are clinics like mine too. I have office hours two times a week in the late evenings. So that people can get what they need for both PEP and PrEP.
CHANDA: Are there any side effects to PEP or PrEP?

KATHRYN: So let’s start with PrEP first because there are different side effects. PrEP being just the one pill. The most common side effects are some nausea, diarrhea, some people vomit occasionally. If the diarrhea is pretty bad we can give you an additional medication to prevent the diarrhea. Also some headache, some fatigue, and really odd dreams—like vivid, kind of Charlie and the Chocolate Factory kind of dreams have been reported. As a general rule, I can only think of one or two patients who had to come off of it because of the side effects. The other side effect is that it can have some effect on your kidneys which is why you need to have your blood test done every three months. We check your kidneys regularly to make sure that the medication isn’t affecting them.

CHANDA: If someone is on other medications, does that ever conflict with PrEP or PEP?

KATHRYN: Not to my knowledge. I always double check before prescribing to someone who’s on a lot of medications. But the really good news is that our HIV population is getting older in addition to getting younger. There are men now who have been a part of that community for many, many years and are now in their fifties and sixties and they want to have HIV prevention. They’re all on a lot of the medications that come with getting older and we really haven’t seen any side effects or problems to date.

CHANDA: What would you say is the best prevention effort to stop transmission of HIV?

KATHRYN: Abstinence.

CHANDA: Oh. (Laughs). Well, of course! What about the second effort after that?

KATHRYN: Well, condoms for sure. But I think the best way to prevent transmission of HIV is for the HIV positive person to be on all their medications, for their viral load to be undetectable, for their partner to be on PrEP, and then to use a condom. If those three things are in place, you will not transmit HIV, period. End of story.

CHANDA: How long can you stay undetected?

KATHRYN: Forever. As long as you take your meds.
CHANDA: I was talking to AKeem and he said the youngest person he’s seen infected with HIV or AIDS was thirteen. Do children take PrEP or PEP as well?

KATHRYN: I think my youngest patient is probably fifteen or sixteen. There are certain clinics in the country where, for the purposes of sexual health, you are considered an emancipated minor. Which means that I can provide sexual health care, and sexual health care only, without a parent. Which is fabulous. That’s how young adults can get it. They’re not children. Children are medically under thirteen, these are adolescents and young adults.

KATHRYN MEYERS

Kathryn (Kat) Meyer, BA,RN,MSN, CNM, DNP, BC-FNP has worked in sexual health for over 20 years. She has been at Metro for years specializing in sexually transmitted infections (STIs). For the past five years she has been focused on getting information on PrEP to the people who could be on it, and combating the rise of syphilis. She is also watching the emergence of antibiotic resistant gonorrhea with some anxiety. When not educating about, diagnosing, or treating STI’s, she is usually embarrassing her children in front of their friends by... talking about STI’s. Kat can be reached, and appointment for the PrEP clinic can be made at 216-778-8305.

PrEP Resources:

metrohealth.org/infectious-disease/hiv-aids-services/prep

pleaseprepme.org

OHIV.org

CHANDA: Although we’ve come far in sexual health, where would you say there are still stigmas and challenges in 2021?

KATHYRN: Unfortunately systemic racism in the medical community, carries a great deal of burden toward the African American community who are distrustful of medicines in some ways. Who are distrustful of the medical machinery, especially in sexual health because of what the medical community did to them in relation to sexual health for so many years. It’s still something that resonates through the community, unfortunately.
Life is What You Make it
A Poem by Derrick Louis

Life is what you make it

Many people think of aids and hiv as a death sentence

But just by keeping your head up you can surpass it

With all the research and medicine out there, that makes it possible to live with it

Because just like with everything.......life is what you make it, and if you lay down and accept defeat; your life will become that of misery rather quickly

I know them three letters can be in fact scary.....but what is more scary is living your life saddled in misery
CHANDA: What is the difference between HIV/AIDS?

AKEEM: HIV is the Human Immunodeficiency virus. It’s the virus that causes AIDS. AIDS is Acquired Immunodeficiency syndrome. You have to have HIV before you can have AIDS. You can’t have AIDS without having HIV first. Some people don’t ever go from having HIV to having AIDS. Having AIDS is a specific medical diagnosis. If your t-cells drop below 250, that means your immune system is now so damaged that you now have Acquired Immunodeficiency syndrome. It can also be medically diagnosed if you have certain opportunistic infections, like kaposi sarcoma and other things that people who have HIV/AIDS, generally get that aren’t seen in the general population.
CHANDA: Can you tell us where HIV is found? Where do they go to find out a person has contracted HIV?

AKEEM: Well, HIV is in five bodily fluids. In blood, vaginal secretions, semen, breast milk and anal secretions. Yes, human beings have anal secretions. So that’s where HIV can be found. Where enough of it, or the environment is hospitable enough. Think opaque fluids. If you filled up a glass bottle with that fluid, could you see through it? If it’s cloudy and you can’t really see through it then that’s a good home for HIV. If you can see through it like tears, sweat, saliva, urine, those are fluids that generally you can see through. HIV can’t survive in those environments. HIV has a very hard time in salvia because we have enzymes in our mouths that break down food but it can also break down viruses like HIV.

CHANDA: Wow, I didn’t know that. If you can’t see through the bodily fluid, HIV can be there. If you can see through it--these natural things that we can’t control that happen to us like tears and sweat, people use those things as reasons to stereotype or say, “I can’t be around that person who may have HIV/AIDS.”

AKEEM: I’ll never get tired of hearing that. “I didn’t know that.” It makes my job so worthwhile.

CHANDA: Yeah, I mean it really breaks down those fears. Which is the whole point of why we’re doing this podcast. Just unnecessary fears and misinformation that not only makes life hard for people who are infected with HIV/AIDS but also, we get to stay in ignorance. It’s not great for us or our communities or the people around us.

AKEEM: Speaking of misinformation, “science hates a zero”. So, I like to ask people, providers, professionals and students, how much saliva has to be present? Because we say, you know, we can’t get it from saliva, but science doesn’t like zeros. So how much saliva has to be present for a person to be at risk? Do you have wild guess?

CHANDA: Am I supposed to guess in ounces or something?

AKEEM: You can guess in whatever measurement you like?

"You have to have HIV before you can have AIDS. You can’t have AIDS without having HIV first"

CHANDA: I’ll say...um, two cups of saliva?

AKEEM: A lot of people say a bathtub full. But the specific measurement is at least 16 gallons has to be present. For a person that produces saliva regularly that’s a little over 4 months of saliva that has to be present. That’s why we say you can’t get it from saliva unless you are ingesting 16 gallons of saliva. I can’t get 16 gallons of anything down. So 16 gallons of saliva has to go down for you to even be at risk of contracting HIV. Not even a 100% chance, just for the risk to be high enough.

CHANDA: Wow. That’s quite a bit. That answers one of my other questions which is, if your partner has HIV/AIDS, can you you contract it from just kissing them?

AKEEM: There are certain activities that are like green light, red light, and yellow light. Kissing is a greenlight activity unless you both have open sores in your mouth, which would then make it blood to blood contact.
For example, if you have bad gingivitis where your gums are constantly bleeding and open and your partner has gingivitis with bleeding open gums, and one of you have HIV, then there is a chance there. There has to be that fluid exchange. Otherwise, kissing is perfectly fine. Drinking after someone is fine. Although I don’t recommend drinking after someone because my mother was very “nice nasty” and she told me not to drink after other people! (Laughs) But you can share the same cup, eat off the same plate, you can hug, and use the same toilet. You can’t get HIV from being spat on.

CHASE: Oh yeah, people can live and have all of the typical things that people who are not positive can have. You can do all of the things that you were doing before you were HIV positive. Just make sure you take care of yourself.

CHANDA: What are the symptoms that a person who is diagnosed with HIV will experience? For example, you said there’s a difference between HIV and AIDS? Are the symptoms different in how they transpire?

CHASE: Well, here’s the thing about all STIs, the most common symptom of every STI is no symptom. Which is why it’s important to get tested. You can have gonorrhea, herpes, chlamydia, trichinosis, HPV, and still not have symptoms. Not everyone has symptoms and not every bacterial or viral infection will show symptoms. But with HIV there are some symptoms that show up but not often. When a person is seroconverting, going from negative to being positive, they can have what we call retrovirus sickness. That really just looks like flu like symptoms and/or a hallmark of rash that comes around or across the chest. But that doesn’t happen very often. A person can have HIV for ten to twenty years before it ever turns into symptomatic HIV. A person can also have HIV for many years before it turns into AIDS. So there aren’t symptoms where you can look at someone and tell, “this is HIV” or “this is how HIV is showing up.”

You should always go and get tested just as a standard practice. If you’re very sexually active I would say, every 3 months. If you’re less sexually active, 3-6 months. If you’re in a relationship that is monogamous and your person is HIV negative you don’t necessarily have to get tested that regularly but once a year would be good.

HIV is a very fragile virus and it needs specific conditions to survive and transmit. Even if someone does have HIV and you have unprotected sex, if the person doesn’t have enough of the virus present within them then your chances of getting it are very low. There’s something called U equals U (U=U). If a person who is HIV positive has been in treatment for 6 months and they maintain an undetectable status, which means that a blood test can’t pick the virus up in their body, then they can’t sexually transmit HIV to anyone. This is why there are people who are HIV positive, have partners that stay negative and they can have children. HIV needs a host. It cannot survive outside of the body in the air for more than five minutes. It can’t be on a surface and it doesn’t go through skin unless there is an opening.

CHANDA: It seems we have advanced. Where someone with HIV can live a life where that doesn’t stop them from being in love, expressing themselves sexually, and having a family.
CHANDA: Let’s dive into a deeper part of this topic. There is a stigma about HIV/AIDS which is mainly forced on the LGBTQIA+. During your work have you found that there are specific communities that are more likely to have positive cases? Is there any truth to this stigma?

AKEEM: That’s the thing about stereotypes. It’s not that they’re necessarily untrue, they’re just incomplete. And that is very incomplete. HIV was first found in gay men. It was called many different things, such as GRID (Gay Related Immunodeficiency Disease), some people even called it “gay cancer”. But HIV does not discriminate between your age, race, sex, gender, or nationality. Anyone can get HIV through a variety of activities. But HIV is still a big problem in the LGBTQIA+ community, especially the G, B, and T communities. When you think about the LGBTQIA+ community and how small it is, then you think about queer communities of color and how small that is, the pool of engagement is smaller. For people who are queer and Black and male it can be difficult to find and have sex with people who look like them. The CDC did release information that Black, gay men have a 1 and 2 chance of contracting HIV in their lifetime. And that has to do with lifestyle choices, and I don’t mean like gay as a lifestyle, but the way you engage with people in your own community. Where you’re from, who you’re around, and who you get to interact with play a role. Anyone can get HIV though. A few years ago the rates were going up for cis-gendered Black women and cis-gendered Latina women. These women got HIV the same ways that other people who’ve gotten HIV can get HIV. So it’s not one specific community that is affected. We’re all affected.

CHANDA: I don’t know if this is a moral question or a logical question but I saw this on a video of this sexologist on Instagram and she asked, “should you tell your partner you have HIV?” What are your thoughts on this?

AKEEM: This is a hot button topic. In many states it’s not legal to not disclose your status to someone you’re having sex with. It actually counts as felonious assault. A lot of us in the HIV fields think these laws are outdated and that they need to be changed because it just further stigmatizes people who are HIV positive. It’s like, “now you must tell everyone” and there’s no real standard of “when is the right time to say this? How do I bring this up?” I think if you are engaged in sexual activity with anyone, it would behoove you to communicate first. The best prevention method is communication.

"HIV does not discriminate between your age, race, sex, gender, or nationality."

The best one. I don’t think that people have an obligation to disclose their entire life to you when they’re having sex. They can control what information about themselves goes out. However, I think a part of communication is letting people know if you have any STI. And I mean one that’s not obviously curable. If you had gonorrhea ten years ago you don’t need to tell me about that. But having open dialogue with your partner is important.

CHANDA: The laws have to change. It feels like there’s an “attack” or a “sentence” on people who have HIV.

AKEEM: Yeah, it’s very stigmatizing. If we look at the history of a lot of things there’s a lot of things rooted in stigmas that are pretty iniquitous. This is one of those things that was made to isolate people with HIV.
CHANDA: If you find out a friend or family member has been diagnosed with HIV/AIDS, how do you respond? Working in this community what are some things you have observed?

AKEEM: You help them. Just as you would if they had anything else. If you had a friend that discovered they had lung cancer you wouldn’t be like, “eww stay away from me I don’t want to get your cancer.” Be there for them. You talk to them. I absolutely encourage people to research and learn. Of course, use reputable sites because it’s some bad information out there. One of the biggest killers in HIV is social isolation. People no longer feel like the person they were before.

HIV is not airborne, it’s not a plague. You have to do specific things to contract HIV. Four specific things to be exact.
1) Share needles--blood to blood. 2) Having sex, specifically vaginal and anal sex. 3) Vertical transmission, from mother to child, by the way there’s a very low rate of that happening these days because during prenatal care we are very efficient in stopping the spread of HIV from the mother to the child. Statistics are less than 2% in the United States. 4) And before 1985, blood transfusions. Now they’re safer and they go through a lot of testing. The chance of you getting HIV through a blood transfusion is less than 0.1% because the blood is tested before it’s used. Blood transfusions also have a stigma because if you’re a man who has sex with men, you can’t donate blood. Although that has changed in most places, people are still fighting that fight.

CHANDA: With the blood transfusions, the lack of logic…(L1qaughs) It seems like it’s coming from a place of prejudice more than a place of science and fact.

AKEEM: It seems even mosquitoes are ahead of us. Mosquitoes are like, “I’m getting this blood and it’s going to my babies”. But humans for some reason...(Laughs)

CHANDA: We’re a little bit slow. We’re catching up though. Two more questions! How can I be an ally to the HIV/AIDS community?

AKEEM: Being an ally is just like being an ally to any other human beings. You listen to them, you look for them, you treat them like any other human being.

People feeling like they have to isolate or being isolated from the social groups they were once a part of. That leads to some really bad mental health outcomes. Reminding the person that “you are still my same friend or lover that you were the day before” and that you have their back and you’re going to get through it together—that can make a world of difference for someone’s outcome. If this is your partner, learn how you both can be safe.

There is a pill called PREP, which is being developed into an injection and implant soon, taking this pill once a day lowers your risk of contracting HIV over 99%.That’s biomedical prevention. Using condoms is physical prevention. Trying other ways of having sex helps too. Oral sex is very low risk. It’s a much lower risk than having vaginal or anal sex.

"Being an ally is just like being an ally to any other human beings. You listen to them, you look for them, you treat them like any other human being."
Follow HIV blogs, Instagrams and other social sites. Share their posts. There are lots of people who share loads of information. One guy named Carlos Cruz out in California called @followmyswallow. He’ll post himself wherever he is in the world with his meds. The more that we normalize, share it, and engage with them, it reaches further and shows other people that these are human beings whose life did not stop because they got a diagnosis.

**CHANDA:** What are some resources that our listeners can go to for more information on HIV/AIDS?

**AKEEM:** You can also go to our MetroHealth website. We have a one pager about HIV, STIs and our clinics. If you do know someone who is positive you can tell them about our app “Positive Peers” which is a social media app where you can make an avatar without putting yourself out there.

You engage with not only the providers but you can engage with other people who have been diagnosed as well. It’s mostly for young people. You have to be about 18-30 years old to join, sometimes there are exceptions. That’s where people can build community. There are a lot of resources. The main thing you want to be sure of is: Is this a medically accurate source? We have an HIV prevention blog called “Pop 2 Block”.

There are blogs, poems and art that came from a contest we had. There’s also a direct link to me if you want to shoot me an email with questions. We love questions! There ain’t nothing I’ve never heard! Feel free to ask questions! That’s one of the number one ways to connect with someone who knows something.

**CHANDA:** You’ve answered a wealth of questions and you’ve given us a wealth of information that can give someone a basis of knowledge to move away from stigma and hopefully toward education and allyship! Thank you Akeem.

Akeem Jamal Rollins is a sexual health educator and writer from Cleveland, OH. He first began educating himself and his peers on HIV/AIDS and other STIs with The Street Crew of Greater Cleveland at the LGBT Community Center. As a safer sexual health educator, he has worked for Kaiser Permanente, City Year Cleveland, The LGBT Community Center of Greater Cleveland, Recovery Resources, and MetroHealth System where he is currently a PrEP Navigator. While not teaching sexual health, Akeem is a poet working on two book, Post Traumatic Hood Disorder and The Lynching of the God Ghost.
What is the difference between HIV and AIDS?

from Bryan C. Jones

"I think a lot of people, even educated people, feel like I shouldn’t use the words AIDS because AIDS is a progressive condition of HIV. HIV is a virus and AIDS is what HIV can progress to. But when I was diagnosed in the early 80s, there was no HIV. There was just either GRID (Gay Related Immunodeficiency Disease) or an AIDS diagnosis. Clinically, once a person has an AIDS diagnosis, you always have an AIDS diagnosis. That’s not to say that your immune system can’t rebound to where you’re healthy but you still have an AIDS diagnosis."

"AIDS is a progressive condition of HIV. HIV is a virus and AIDS is what HIV can progress to"

Personally, I always say “thriving with AIDS” to pay homage to those people who didn’t make it. To my friends that I lost before HIV became manageable. It also gives blessings and honor as to why I’m still here. I haven’t been living this long with it because I’ve done everything right. In fact, at one point in my life I did everything wrong. I’m still here."
Mental Health Corner

with Jennifer McMillen

What is mental health and emotional health?

If a person has mental health then I feel like it’s almost like an absence of certain things. An absence of certain stressors. Or it’s the presence of lots of coping skills and resilience to deal with something. I think that we all go through things that can make us sad or make us grieve. In some instances, unfortunately, a lot of us go through things that cause trauma. We’re human beings so when those things happen, we can really struggle. Mental health is about when those things happen. I honestly think at some point we all will struggle with mental health. It’s something that unifies us all as human beings. Of course there are people who have much more struggles with mental health than others such as people who have a mental illness or a mental health diagnosis. The thing about mental health is that it’s connected to your body and your environment. It’s connected to some people’s spirituality. We have to be intentional about taking care of all those aspects of our health and well-being.

What are some ways that someone with HIV/AIDS can manage their mental health?

Human connection - "Make the effort to go out there and connect with people who support you and love you, that is a really good way to take care of mental health."

"Support groups for HIV are great too because your best friend can and will listen to you but they don’t understand first hand like support groups can."
Mental Health Corner
with Jennifer McMillen

Who's Who?

Jen McMillen Smith I’m a social worker at MetroHealth. Primarily working with those with HIV. I do support groups for many different people living with HIV. I help physicians, nurse practitioners and other providers give HIV positive test results to patients. I also provide counseling and education, link them into care with our infectious disease clinic where I help get them rapid started on treatment for HIV. I supervise some special projects. The PrEP Navigation project here at Metro Health. PrEP is a pre-exposure prophylaxis for HIV prevention. It’s a pill you can take once a day to not get HIV. I am also the project director for a project called “Positive Peers”, an app that we’ve designed, tested and are now scaling up across the United States, especially for young people with HIV. That’s what I do here at MetroHealth, special projects dealing with HIV.

What are some ways that someone with HIV/AIDS can manage their mental health?

"Time does help people with the adjustment to a positive diagnosis. At first it’s this shocking, terrifying information. But people are supported as they’re educated and empowered to do something about their health."

"See a Counselor - but ultimately answers are within! It’s our job to prepare the environment so that way you can come to your own conclusions. It doesn’t matter what I think. It matters what you think, what you experience and how you feel."

"Family of Choice" - One other thing about trauma is that we all have a family of origin. We can’t help where we were born or who we’re related to. A lot of times in my support group I hear people talking about, “my family of choice”. I think that it’s important that we open up our view of who our family is and then we can be surrounded by people who know us and know our worth.
D.I.R.T stems from a number of areas that have affected my life. It mostly stems from a social consciousness that Black folks have. I saw the epidemiology or the data that’s being handed down that says Black people are most at risk for contracting HIV and carry the brunt of the new diagnosis. It should be no surprise that we are. We are most impacted by everything. The system is not designed to help us. It is only designed to hinder us. I often saw millions of dollars being dispersed and earmarked for Black communities but it never reached the community. When you got out on the ground of that community, you never saw these millions of dollars on the street. A lot of agencies that got this money would develop pamphlets and put it in the library at the top of the hill but the pamphlets would never reach the bottom of the hill where the people are actually living.

So D.I.R.T is an acronym that stands for Direct, Inspiring, Reachable and Teachable. It is for Black folks who look like us, live like us, and talk like us. It’s conversation that’s stripped away from all pretense. You have to cultivate that “dirt” before anything can begin to grow. Our communities have been impacted in so many ways from so many other issues such as gentrification, redlining, etc. We’ve lost the sense of community because of these things. The misconceptions for people who do prevention and outreach are that Black people don’t want this information. However, Black people welcome this information. You’ll be surprised when going into the community how welcoming they are and how much they need it.

I first started this outreach in Garden Valley and have been doing it since 2013. It was a welcoming space because Jan Ridgeway was on the same page. She’d often say, “don’t give me money if you’re gonna tell me what to do. Give me the money to take care of our community. We don’t need you to save us. We can save ourselves. We don’t need a hand out. We need a hand up.” This gave me an understanding of what I wanted to do with D.I.R.T advocacy. The health departments were not saving us. The initiatives that they were developing weren’t reaching us. It’s time for us to save us.
“We Think 4 A Change” targets those dealing with disorders. People who are or have been unfairly judged and discriminated against. We try to advocate for those who have had difficulty accessing care because of their finances, where they live, who they are, and other circumstances.

Why?

The fear surrounding the emerging HIV epidemic in the 80s, largely continues today. At that time very little was known about how HIV was transmitted, which made people scared of those infected due to fear of infection. In Cleveland, roughly 1 in 8 people living with HIV is being denied health services because of stigma and discrimination. So adopting a human rights approach to HIV and AIDS is in the best interest of public health. This is key to eliminating stigma and discrimination.

What Michelle has learned as a Black woman:

What I learned is inaccurate information about how HIV is transmitted. How inaccurate information creates irrational behavior and misperceptions of personal risks. There is no one way to advocate. It really depends on what’s important and inspiring to you. Advocacy must start with open and honest dialogue. Being an advocate is important to me because I believe the only way we are going to eliminate the stigma, judgements and discriminations surrounding who we are as people is by putting our names and faces on our stories.

"The term stigma is not stationary. Meaning stigma does not lack in movement. As a cultural experience, stigma changes over time just as public values, attitudes and preferences in many areas of life."
"Being told I was HIV positive was the most terrifying words to hear attached to my name. I struggled with so many complicated life changing challenges for years. From depression, anxiety, abuse, self hate, and many more devastating situations. Realizing that I hadn’t accepted my diagnosis; years of emotional turmoil plagued me, and I struggled to be and feel normal. I had a moment of truth however, after realizing that there were, in fact, other individuals living with HIV, and we were no different than someone that was not positive. In this book, I will be sharing with you my personal perspective as a woman living with HIV. Maybe you’re curious to know the thoughts of a person living with HIV? A woman trying to live with HIV? Or a woman looking to embrace her journey in whatever stage of her life while living in secret. This book will send clarity of not only living with HIV, but living with purpose through surviving HIV."

- Chatrivia Kennedy
SPOTLIGHT: A Day in the Life of a “Positive Peers” App Admin!

CEDRICK TAYLOR

Meet Cedrick:

Cederick Taylor is working diligently to bridge the gap between patients and healthcare as a MetroHealth Patient Navigator. As someone who is living with HIV, Cederick is skillful in establishing healthy relationships with his patients and becoming an advocate for individuals in need. This allows him to soar as Admin for the app “Positive Peers”. Cederick is full of curiosity, he finds joy in cycling, musical theatre, canoeing, modeling, DIY projects and massage. With the goal in mind of creating a talkback series around HIV and Community Health & Wellness, he strives to continue his education as a Community Health Worker.
I was born and raised in Cleveland, Ohio. Itching to get out of here, but it is a great place. I grew up with a really large family on the east side of Cleveland. Our family is arts driven so we have writers, architects, dancers, actors. It’s something I was raised around and what I want to do long term. I want to open an institution for something like that. As an adult I am interested in photography and film.

Presently, I am HIV positive and have been for three years, almost four. At that point my life kind of took a turn. In that time I’ve found out a lot about myself and others. I gained a mutual understanding. It allowed me to have a sense of compassion, a love for other people, and myself. It makes me respect all things.

Right now I’m doing some work with MetroHealth as an admin for the app “Positive Peers”. Just before I got involved as an admin I was actually a user in the app. I now have the understanding from the outside and the inside. We have a joke with the rest of the team where they call me the “Dad-min”. Like one of the “OG’s” of the app. I also do patient outreach which is contacting individuals who are out of care. It’s very important that we get those people in care and for them to stay in care.

What is the Positive Peers App?
"It’s for individuals who are HIV positive, young adults, 13-34 years of age."

What’s the most challenging part of being a patient navigator and helping manage Positive Peers?
That’s an easy one for me! Number one, I’m human first. Second, I’m a person diagnosed with HIV so I have some of the same thoughts and questions as everyone else. What frustrates me is that I cannot help all the time because I don’t have all the answers. Someone can feel like, “this is the end. It’s over for me.” And I’m a tough love person. I’m like, “it’s fine that you feel that way but get over it. At the end of this really short tunnel, there is light and this is how you’ll get there.” I try to separate myself from just being the admin in the app. It works out so well. I’m very mindful of what people are saying and what people are feeling and I’m not always the one interested in taking the lead. I let conversations happen and I’m open to being checked if others feel it’s needed.

Ced What Now?
CEDRICK!
"I was born and raised in Cleveland, Ohio. Itching to get out of here, but it is a great place. I grew up with a really large family on the east side of Cleveland. Our family is arts driven so we have writers, architects, dancers, actors. It’s something I was raised around and what I want to do long term. I want to open an institution for something like that. As an adult I am interested in photography and film.

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What's a day in the life of a Positive Peer admin?

My day is blended. I’m doing patient outreach and admin in the “Positive Peers” app.

In terms of the app, I’ll usually jump in, read posts and private DM’s. I’ll get questions like, “last night I took my medication with a shot of Jack, what’s going to happen?” Similar to Facebook and Instagram, “Positive Peers” app has a timeline. Everyone on the app comments often on it.

We also hold support groups on Zoom and I post that into the apps every first and third Tuesday of the month.

The app itself is open enrollment. Everyone in the United states who is HIV positive, 13-34 and has a smart phone has access to this open forum.

I share about my day and ask people to chime in. Encouraging words are always posted and we don’t tolerate any bullying in the app. I stay on the front end of that and I keep my notifications on.

There’s everyone commenting with each other but there are also video vlogs that people can look at. I watch those before they get published and I also update our resources.

If someone in the app is having a hard time finding housing then we provide the information they need to help them in the app.

We have a wellness tracker. If you’re taking your medication you get points. If you read our blogs you get points. Communicating in the comments gets you points as well.

The app gets pretty busy. There’s no cut off time, it’s always booming, even in the middle of the night.

I do struggle with just being somebody who’s also on the app because I have similar emotions. There are days where I don’t feel like taking my medication. There are days where I take my medication and it’s a wrap for the rest of the day in terms of my attitude. It makes it really interesting because when you’re going through that and someone’s asking you how to get through it, it’s kind of hard to be like, “just dribble the ball!” It’s always a push everyday, which I like because I like challenges. It’s always something new every time.
Being a user in the app. Jennifer McMillen, who you spoke with before, gave me my diagnosis. I spoke with her and she introduced me to the app. I explained to her the type of dude I am. I want to be out there, on the stage, in front of the camera and on everybody's screen. When I described that to Jenn, I was introduced to an opportunity to speak at Case Western. I was able to go there and share my story only a month into my diagnosis. It was fresh. That led to speaking at other institutions, having other interviews and doing “Tales of Triumph” (Positive Peers Blog). After doing that, Jenn asked me, “What do you want to do in life?” After being diagnosed I separated myself from the dreams of fame and art. I didn’t disconnect all together but I did an entire holistic evaluation. For me, I want to help other people not feel how I felt when I was diagnosed. I want people to be educated. I don’t want people to be put in this position. If you are, I want you to learn how to navigate through it. This helped me to learn to be selfless. I don’t say this to pump myself up. You legit have to be selfless because it’s a team effort. For people to disclose to me, that’s a whole other situation. There’s prosecutions around that. So then I think, “how do I help the next person to not end up in that situation.” So Jenn mentioned that they may have a position soon called a “patient navigator”. I was interested because I hated my job! I was selling the internet and I was bad at it! Jenn told me I wouldn’t be rich but I’d get into something that gave me purpose. I had a few interviews which were more like conversations of how I would interact with people. You can’t just place anybody in these roles. You have to have lived experience or have the care and drive for it.
Quick Facts

Youth With HIV

When compared to all people with HIV, youth (aged 13 to 24) have the lowest viral suppression rates. For every 100 youth with HIV in 2018:*

- 55 received an HIV diagnosis
- 43 received some HIV care
- 32 were retained in care
- 33 were virally suppressed

For comparison, for every 100 people overall with HIV,

- 86 received an HIV diagnosis
- 65 received some HIV care
- 50 were retained in care
- 56 were virally suppressed

* Includes people with diagnosed or undiagnosed HIV.


Source: CDC. Selected national HIV prevention and care outcomes (all ages). Based on the most recent data available in December 2020.

NEW HIV DIAGNOSES AMONG WOMEN & TEEN GIRLS

- 16% HISPANIC/LATINA*  
- 19% WHITE  
- 61% BLACK/AFRICAN AMERICAN  
- 5% OTHER

* Hispanics/Latinas can be of any race. Based on the latest data available in February 2018.
Community Voices

Images from community voices on Instagram.
Top left: @drcarriefoote
Top right: Image of Ashley Cason Education Specialist & Prevention Specialist at @cancommunityhealth from @browardhealth
Bottom left: @mrandrewkeates
Interview with Dr. Ann Avery

A CONVERSATION ON HIV/AIDS WITH CHANDA BYNUM

CHANDA: Tell us a little about yourself. Why did you become a doctor? What do you specialize in? How long have you been working at Metrohealth? What do you love about your job?

DR. AVERY: I’m from the east side of Cleveland. That’s where I grew up. I went to a public high school. I went to Case’s med school. How did I figure out I wanted to be a doctor? I have to tell you that I thought it was a cool idea. I was always a science and math kind of kid. My parents told me there was no future in math and so I should go into sciences. In high school we dissected a fetal pig and when I found that I could actually stomach that, I was like, “Okay I can go be a doctor now.” I went off to college with the idea of being a doctor but within a year decided that maybe it wasn’t for me.
So I changed my major. For everyone who isn’t sure, it’s okay to change your mind. I became a psychology major with a minor in Spanish. I was working with a psychologist and I took the graduate exams for psychology school and did really well on the science side but average on the language side. The psychologist said, “why aren’t you going to medical school?” I switched back and finished the prerequisite for medical school. I was glad that I did that. It’s a long journey and it’s intimidating. Sometimes it takes a few twists and turns to get there but I’ve loved every minute of it. I started as an emergency medicine physician and changed my mind again. I was like, “this isn’t what I wanted to do.” After a year I switched to medicine training. I did additional training for infectious diseases down in Miami. In 2004, I returned to Cleveland and I’ve been at Metro ever since.

"HIV does not discriminate between your age, race, sex, gender, or nationality."

CHANDA: I always assumed that people with science and medical minds are always so sure about what they want to study. That their minds are always made up. I guess that’s not always the case, is it?

DR. AVERY: That isn’t always the case. I’ve been able to merge all the passions that I’ve encountered into what I do currently. The psychology background helps me with a lot of the mental health that I handle within the office. I can speak Spanish to patients so I continue to use my Spanish training. The medical training has been, obviously, essential to be able to take care of patients as well. To be able to use all three as a physician has been amazing.

CHANDA: What do you love about being a doctor at MetroHealth?

DR. AVERY: I did my residency at Metro. I left Metro and worked in Arizona briefly. In Miami I was in a hospital very similar to Metro. I was at Jackson Memorial. Then I came back to Metro because I really love the mission. The mission at Metro is to serve patients regardless of their ability to pay and provide the same care to all patients. To do that through learning service and research. What I have enjoyed at Metro is that I take care of patients and I don’t worry about whether they have this or that insurance. We have so many wrap around programs and support from the community to be able to take care of our patients regardless. It takes that pressure off. Also the patients that come to Metro are so appreciative because that’s not the way it is for them at other locations. Sometimes they come to us because they’ve been turned away elsewhere and because they really need care.

CHANDA: During my time interviewing and researching I’ve noticed communities that are most at risk of contracting the disease are often people marginalized in society due to their gender identity, sexual orientation, race or ethnicity, economic status, lack of education or general stigma surrounding the disease. When considering that information can you tell us of anything you may have encountered as a doctor concerning societal and social economical issues when servicing patients for HIV/AIDS care?

DR. AVERY: That’s a great question. It’s a big question, too. Probably the million dollar question. If we could answer it we could end the epidemic. One thing that’s important to understand is that HIV is a disease of poverty.
If we look across the country at data, nationally, there is a huge race disparity. But when you actually correct it for where individuals live, if they live in poverty there isn’t the same racial disparity in prevalence of HIV disease. It’s more a disease of poverty, in my mind, than a disease of racial disparities. That being said, African Americans are overrepresented, as are Hispanics and Latinos. What I am struck by is patients that are newly diagnosed with HIV and that they may have heard about HIV, or are aware there is medicine but there’s so little knowledge about what the advances are. Especially in individuals who have not graduated from highschool but didn’t do additional post high school education. The lack of knowledge also adds to stigma. If you don’t know then you are fearful. Fear and stigma add to reluctance of care, unwillingness to share your status with other people, which also stems from someone having something negative to say about someone with HIV even if they don’t know their status or the other person’s status.

CHANDA: Some articles I’ve read also suggested that some people believe that how someone behaves sexually can be linked to their race, class, gender, religion or sexual partners. Would you say that there is some truth to that?

DR. ANN AVERY: No. I mean we are sexual beings. I think that all of us will be sexually active at some point in our life and there are times in our life where we’re more sexually active or less sexually active. I think that’s one of the greatest challenges to preventing new individuals from becoming HIV positive as well as engaging our young people into HIV care if that’s what they need.

I would say the most common reason I hear from someone who’s newly infected is that they heard about HIV infection but they didn’t think that they really needed it. They didn’t think that they were that person who was at risk. There’s also the sense of “invisibility” that most of us have when we are 15 to 24 and that decreases as we get a little bit older. Some people it decreases faster, some people it doesn’t decrease at all. To me there’s not one group because you’re this color or this gender that’s more sexually active or more at risk. In fact they’ve shown the opposite may be true, especially if you look at small subpopulations that are already in our priority groups. When we think about any sexually transmitted disease we think about what’s the background of your community? If your community has a higher prevalence the chance of being exposed to it is higher. If that community has more untreated HIV then your chance of being exposed is greater.

"HIV does not discriminate between your age, race, sex, gender, or nationality."

CHANDA: Do you have any structural intervention ideas that communities could do to impact and change what’s happening in some of these communities?

DR. ANN AVERY: When I think of structural interventions I think about how we can change a part of a puzzle. So housing interventions, educational interventions, insurance barriers. The things that come to mind are looking at job retraining and vocational educational programs to get people who are underemployed into employment to create stability. Then pairing that with housing.
One of the things that I have seen, particularly for our young people who are newly diagnosed is that they’re often living in a place of instability. Especially for our gender minorities who identify as the opposite sex or prefer to have sex with the same sex, often have greater challenges because of lack of family support. They are more likely to end up in foster care or living on the streets because they got kicked out of their own house. They sometimes don’t have a typical nuclear family of support. That puts them at additional risk because of potential trauma and potentially needing to have survival sex. They may be needing to have sex to have a place to sleep, have something to eat or just to have some money. These risk behaviors put someone at higher risk for HIV and other challenges. If we can get to those structural interventions, that would be potentially very influential.

RESOURCES

 metrohealth.org/infectious-disease/hiv-aids-services/prep

 pleaseprepmef.org

 OHIV.org
10 Things I've Learned by Chanda Bynum

1. HIV is no longer a death sentence. People are living full lives, having children and even going undetected indefinitely by using medication which can be taken by mouth or by inoculation.

2. HIV/AIDS is not a "gay disease". Anyone from any community no matter how they sexually identify can be infected.

3. There are still unfair laws against people with HIV that force them to disclose their diagnosis. It’s nobody’s business about anyone’s health issues except who that person wants to share with. These laws have to be removed.

4. HIV/AIDS disproportionately affects the Black community because of stigma within Black culture and culture in general, lack of sexual health education, and lack of funding being allocated to Black neighborhoods.

5. You do not have to have HIV/AIDS to be an ally. This problem involves us all.

6. HIV is not transmitted through any bodily fluids that are seen through such as tears, spit, and sweat. They are transmitted through bodily fluids such as blood, semen, vaginal secretions, breast milk and anal secretions.

7. You’d have to drink 16 gallons of saliva from someone with HIV in order to get HIV from saliva. For a person that produces saliva regularly that’s a little over 4 months of saliva that has to be present!

8. PEP, or post-exposure prophylaxis, is a short course of HIV medicines taken very soon after a possible exposure to HIV to prevent the virus from taking hold in your body. You must start it within 72 hours (3 days) after a possible exposure to HIV, or it may not work.

9. Pre-exposure prophylaxis (or PrEP) is a way for people who do not have HIV but who are at very high risk of getting HIV to prevent HIV infection by taking a pill every day. The pill (brand name Truvada) contains two medicines (tenofovir and emtricitabine) that are used in combination with other medicines to treat HIV.

10. For those who do have HIV/AIDS, surrounding yourself with people who love you no matter what, a personal purpose/mission, support groups, and things you enjoy doing is a good way to keep your mental health in top shape!
"My Dog Diva Pearl is my strength ....she gives me the inspiration to rise each morning, take my meds, knowing that she's depending on me. She loves me unconditionally despite of my status . When I look into her eyes they say, "We are in this together." DOG spelled backwards is GOD. Because of her I'm adherent to my medications allowing me to reach undetectable. Undetectable or U=U (Undetectable = Untransmittable) means that if a person living with HIV and is on medication and its controlling their virus THEY CANNOT TRANSMIT HIV TO THEIR SEXUAL PARTNER." - Bryan Jones
Want to share your story?

Go to www.artofme.org for more information
follow us @artofmeorg