



Library podcast

Community HIV Cure Research Workshop - Afternoon Session – Part 2

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[00:00:36] This podcast is being presented in two parts. You are listening to part 2

[00:00:42] All right. So Moses is going to come down. He's going to talk to us about African myths and misconceptions about a cure and HIV. And this is Moses supercharger. You can come on down come on down and start making it down.

[00:00:58] All right. Applause. Also why do you look you look good. Can

[00:01:08] You guess what.

[00:01:10] Good evening ladies and gentlemen. I want to start my presentation in a different way. But I think for you a little song that you can energize it will beat.

[00:01:22] I say my mama. I am uh I am. I'm a..

[00:01:29] Q Well without you can you tell your friend that knock you out without you. You tell your friend. I am my mom.

[00:01:37] Uh hi. Ma'am ma'am uh hi ma'am ma'am I know. Q uh we uh.

[00:01:44] T Okay thank you so much.

[00:01:48] Applause Ladies and gentlemen I'm called Moses supercharger.

[00:01:55] I'm a person has been living with HIV since 1994. And I tell you I've taken medications for the last two decades and it's not easy at all. It's not easy at all but one thing I have a supercharger. I know the cure is coming is coming it's not coming next year but it's coming. D Yeah. Yes. And I was very disappointed this morning when I had a colleague was saying is really disappointed it looks like

he's not going to have a cure in his lifetime. I tell you my bro two years before Timothy Brown was announced cured. Nobody believed that there would ever be a pass on cure of HIV. But here we have Timothy Brown. I have got to continue believing in our research as in our advocacy. The cure will come I'm telling you the topic I'm going to talk about is called African myths and misconceptions about a cure. I had an organization called stigma this Uganda is an organization of young people born and living with HIV in Uganda. I'm also a member of the I S cure advisory board. I also chaired the Joint Clinical Research. Center Community Advisory Board.

[00:03:14] I'm a member of insight club which actually brought me here. I didn't get a scholarship for crying but inside I had some prayer meetings which happened yesterday about one and I requested them to extend my ticket so that I can attend this meeting.

[00:03:29] Thank you so much insight and I happen also to be a member of the A C G G. I was a serious member rep for the Arts Committee. The background I come from you got up from Africa the most beautiful continent in the wild which has a population of one point three billion people contributing 20 percent of the global population but I tell you it's very unfortunate and sad that out of 36 million people living with HIV. Twenty seven million. In my beautiful continent Africa can imagine we have seven continents or rather while if you divide six between if if you divide thirty six between the seven continents you'll get at least five or four million from each continent. But 27 million people are in just in one continent. And that is a big concern. Why do we want a cure in Africa. The pattern of taking medications every day. I tell you I've taken medication I tested in 94 but I had not access treatment until 1998. I started treatment in 1998. I've taken medications and these medications that I take are not good at all. I was hearing super Bush saying he's taking nice stops taking one pill lady my Ecuador's you are taking it a nice job take one in a day in the US. But this is not happening in my continent right now. I'm taking seven huge tablets every day can imagine. And there really have bad side effects. Every time I take them in my stomach I need to go to the restroom and I can't take them without food you know people I've ever tasted European ever and you don't have in combination with corned beef or what it means I'm taking that love Yeah only the separate. Those are seven down beat tablets every day. And I hate them but I love them because they have really made me what I am now I'm strong and be able to do what I do because of those tablets. We want the cure because of the mortality rate that so many people are dying because of HIV I imagine in Africa every year.

[00:05:54] We lose three hundred and forty folks every year in my continent. We don't want them to die we want a cure because of the cost.

[00:06:07] We can't manage buying it out of these for ourselves 90 percent of all the funds that we use to buy the medications and to manage HIV and AIDS in my country are paid by United States of America. Can you put your hands together for us ladies and gentlemen. But America also has domestic problems which needs funds to make their move

[00:06:39] But they are paying these medications every day. The fear is one day somebody will wake up and say enough is enough. It's time you manage your business. But I tell you my country can only under 10 percent 98 percent is being managed by United States of America through before. We want

the cure of HIV stigma. Can you imagine in my country you cannot get married a person before they teach you you cannot be waited in charge before their pastor gets low about your status there is a lot of stigma in my country so much business and so much money is being collected from countries like Oman China Arab countries and so many people are going there for greener pastures. But these countries test for you to get a visa to go to China for you to get a visa to go to United Arab Emirates. You must be tested and so many folks are very disappointed in Africa. They can't go for these jobs because of HIV. The top 60 you know the option. Ladies and gentlemen as I speak right now in my country we have a problem of HIV drug resistance and you have folks who own that line 1300 in Uganda are on the sideline and they have no option if that medication fails is the end of them. So they are praying every day for a cure to come ladies and gentlemen. Let me go to the next slide. Quickly I want take so much longer the misconception on myth which I'm going to talk about are basically based on personal and unguided reasonings. And before I came here is a gentleman I organized the civil community meetings to interact with different community groups to ask them about a misconception they have about HIV cure and this is the report ladies and gentlemen majority of the folks in Africa think that separation is cure majority of people in Africa on at think actually that where you get suppressed you can stop medication and in a group which I interviewed about this issue a young man stood up on say they tell us that actually out of these kill the virus and actually when they do my face when they did my first viral load I had two million virus in my body when I did a second vital Lord they told me it was below 100.

[00:09:20] When I read this second viral load do I. They told me it was around 1000 and I started asking myself Where did the rest go. It was killed by HIV. So he started thinking that the more you take the more it will be killed and you reach a time when there is no more HIV in your body and when this guy was told that he was undetectable. Guess what he stopped medication he thought he was cured so we need more education in Africa to tell people that undetectable is not cure. We need a lot of education about this complicated issue of reservoirs which is even disturbing our research has the biggest culprits of this problem are the young people new prevention and treatment tools are taking so much space for the HIV cure research now in Africa. We think that actually the people who are supposed to find us the cure.

[00:10:31] They look at the treatment which we have today and see if they can leave if they have a hair for life.

[00:10:37] Why waste the energy and funds into finding the cure let them take their medications let em for one by one that is the thinking in my continent. Africa Americans and Europeans have a cure

[00:10:53] And they're hiding it away from Africans. This is one of the misconception on myth that is in Africa. And they have reasons to back this they say. Timothy Brown was cured 12 years ago. He's an American. He was cured in Europe. Why not in Zimbabwe. The drugs that they use to cure Jim with Ray red brown Turabi had been hiding there hiding them away from us because they being been hearing about him with a brown team with Brown for for last last live in yes I tried at one point too to get some or at least to find Timothy Brown to come to our appointment at least to do some interaction with me with our economy or our community. But which I lacked funds to do that. But we need that in

future. Then I interacted with his young people. I told him if you say that Americans and Europeans actually have their Q Under hiding it Junior that in America the 1 million people with HIV who told them I traveled to America like three times every year. I have friends like like Jim Pickett are living with HIV and they are Americans. So your argument is wrong. And one replied that I read that actually majority of the people with HIV in America are blacks and I think these are blacks from Africa going to America already infected I was like oh my god so there is a lot of confusion around that. We need to explain to these communities about Timothy with a brown witchcraft is a big problem in Africa witch doctors are cheating patients telling them that they actually have the cure of HIV. Ladies and gentlemen witchcraft doctors are within reach the extent of sacrificing people.

[00:13:12] To get blood they sacrifice negative people to get their blood so that they can clean you and get you out of HIV on top.

[00:13:24] You can see that this strain is like the clinic. That is the clinic for the witchcraft doctors in my country. The photo you see down there. Is a witchcraft doctor in my country Uganda recently arrested after he had killed five people. And those are dead bodies you see. And the gentleman you see is one of the policemen standing beside this guy was arrested. We have five dead bodies in his shrine. He killed them sucked his blood to clean HIV positive people to get them. Albinos and young children are falling into this. They're being killed in Africa. Thinking that actually their blood can cure HIV it's terrible. There are no legislations for witchcraft. Doctors in Africa. Some of them actually even advertise on radios and televisions. Pastors on profits cure HIV. That's why they claim they tell people to just pray don't take your medications just pray God will heal your HIV.

[00:14:44] As a result some folks are abandoning it out of these everyday this partly explains why we have the highest rates of HIV drug resistance in the world while my country I know has 15 percent can imagine 15 percent what really annoys me is that actually the relatives of these pastors who tell people to stop medications when their children fall sick they don't tell them to pray they take it into hospitals for treatment.

[00:15:23] It's terrible. Majority of these pastors are being funded by pastors from America they get millions and millions of dollars to construct churches you see that judges in my country that church you see is in my country and it has about 2000 followers and we have so many Pentecostal churches I believe in God and I know that God is there but I don't tell people to leave. Medications take your medications as you pray to God to bring the cure that sensitive Miss sum. I actually think that there is an intelligence international intelligence body that from the virus. And for you to get the cure you need to sit down with that intelligence if they formulate this virus. They actually have the cure. That is their argument. Fund us advocates and pharmaceutical companies the idea that reporting pray exposure prophylaxis and combination and will provide therapy and vaccine research is missing in cure research. And in Africa we are asking why. There is a lot of energy when you talk about PrEP Prep. Perhaps half way a prep. There's a lot of fun in prep there's a lot of meetings in prep but when you talk about Cuba people start to advocate we we are not doing enough. We need to act top so that we can defeat HIV pharmaceutical while is very slow indeed comes to Cuba. That is the thinking in

Africa. That the pharmaceutical while is not so active when it comes to Cuba. That's why they think in Africa.

[00:17:23] But when it comes to treatment when it comes to exposure prophylaxis every scientifically conference they will have a new drug every scientific offering that we have discovered this one we have discovered this one.

[00:17:37] But when it comes to cure when it comes to funding 80 percent of the funds that does the cure site come from United States of America where other continents. Why do they want to cure Africa leaders who have so much money. Which is window everyday. Can you use some of that money to invest in Q1 sites ladies and gentlemen that picture you see this guy is writing for a cure. But if funding is going in the opposite direction. He is writing for the Cure and he needs funding but funding is going in the opposite direction. The media is confusing people in my country as I speak right now. People are buying Greek every day mixing it with these thinking that actually a can cure you and the media confused the people when a trip came.

[00:18:46] There was a big story in this very paper that a vaccine has being discovered until we had to intervene and explain that actually exposure prophylaxis is not vaccine.

[00:19:04] To a breakthrough even when there is a cure breakthrough. People think that it will still be for the rich people. And it will take long to come to Africa like art. Remember when you started taking art it took us almost seven years to get art. Do you think it will be very expensive. There are some problems which are confusing folks in Africa ending HIV by 2030. I was in my life recently interviewing people and actually some of them told me that actually HIV is going to end by 2030 because they have had that you know AIDS is bringing in cure in 2030. That's why the slogan ending HIV by Twain that I was selling it. Why do you think like that. Yeah. You need these advertising that HIV AIDS is going to end by 2030. So we need to do more explanation on that. Actually this program is not about Cuba. This program is agitating to put 90 percent of all folks on treatment and 90 percent of all those who are being put on treatment must be suppressed with the intention of not passing the virus because when you are suppressed you don't pass. How about is we have a lot of herbalists in my country. They even advertise on radio stations. These are by stuff you didn't go step stepfather stealing out of these grinding them adding them without local staffs and giving them to clients noticed to be eating half testing equipments they will test you.

[00:20:52] I know that you actually have tuberculosis. They all get TB medications crashed and added with a habit made you see and give you it's very dangerous. My friend in conclusion fake news lies and misinformation about the HIV cure gives false hopes for folks with HIV and threatened to reverse the good news. The good work being done by UNAIDS and its global partners in HIV by 2030. A lot needs to be done to create and empower community advocates with the facts about a cure. Of HIV and the ongoing global cure research so that they can be able to pass on this vital information to the crossword. Some of the impossibilities in 1990 are now possibilities due to the enthusiasm and commitment a cure over HIV is very possible. If we all stakeholders can agree to double the enthusiasm energy and funding. Ladies and gentlemen I want to end with this slide this slide is an

adherence to the additional Center which I'm constructing in my continent because of the problem of resistance because of the problem of empowering people about all these issues about the key lies about.

[00:22:17] Bad myths and misconceptions. I started constructing an adherence to habitation center where young people can come and get empowered this center has taken more because I don't have any fun there. I use personal savings and savings from false friends so they appeal which I want to make. Though I didn't ask Rich at all to give me permission it is usually folk out there who can assist us roof.

[00:22:48] The first floor your welcome roofing. Just the first floor needs five thousand dollars and if you are there and willing to support us with a ten dollar twenty dollar you can send to me remember a bag of cement in my country cost just ten ten dollars ten dollars. Ladies and gentlemen this center will be used to empower young people to help them take their medications to help them fight the myths and misconceptions about a cure of HIV. Ladies and gentlemen advocates let's empower young people.

[00:23:23] When you look in this room majority of the active advocates now are above the age of 45 and my equals sign is that in the next 20 or 15 years if we don't involve young people right now to become advocates we won't have successors to take on our work because you don't expect gym to be as active as he is now in the next 20 years. So we need to start thinking of ways of involving young people in these meetings that we have. Thank you so much.

[00:24:10] Do you have any questions. Talked about fake news. To what extent are fake medicines also an issue in Africa. There was one question and then have you also looked at perceptions of long acting art and how that would change the landscape in Africa. I.

[00:24:27] The thickness fake fake medicines and then long acting treatment the fake news The fake Medicare the fake traditional medications yes really. So much in my country as I say there are so many herbalists and traditional doctors. Who use fake medications to treat to treat people it's too much in my country. Hope I've answered your question and the long acting therapy. This is a new thing in my country and actually people heard about it and there is a lot of question about it. But there is research going on in my country and Uganda is taking part in long acting therapy research. But we have not started taking it in my car.

[00:25:17] I Moses thank you for such a fiery talk. I loved it and I just wanted to sort of reiterate something that you shared which I only learned through our Facebook page for defeat HIV which is under attack every day by three to five spell casters. I don't know how they've gotten so savvy to use Facebook against itself but they create fake profiles or they steal people's profiles and they hit up our page trying to hit the comments sections of every post we make and I just wanted to let people know that if you run an HIV thing on Facebook you're open to it and if you want to find out the way to block them I have figured it out and it's not by touch talking to Facebook. Basically Facebook gives you a way to ban words that can be used in the comments section. So I banned words like herbal Temple

what's app because they're always asking you to contact them through WhatsApp. And the only other thing I wanted to add about that is that when someone replies to those things they're not only getting ripped off for an HIV cure they're opening themselves up to blackmail because if you believe in spells you also believe that oh if you're not going to pay me a certain amount of extra dollars I'm going to put a spell on your husband or on your son. So something else is going to happen. So once that happens because I've gotten that feedback through Facebook as well so it's a really difficult paradigm to work in. But there is a way to get around it. So again you can ban the words that they'd like to use. Most of all somehow they know how to make these bots though and that's the weirdest thing if you think about these traditional medicine healers being able to use bots to kind of spam my Facebook page. I just wanted to add that to you.

[00:26:50] Thank you so much. Hi. I have a question about collaboration. I care really deeply about the cases that are happening in Africa including Uganda. But what are the barriers to me being more invested in caring is the very direct messaging against LGBTQ folk. So my question is how do I as an LGBTQ person assist across that barrier and that boundary considering that there's a death penalty for LGBTQ people in Uganda.

[00:27:21] It's very very good you ask that question. Uganda is one of those countries that criminalize LGBT people and they are really facing it rough to access treatment. They're really facing it hard to get to enjoy their country of course because they are also human beings and accessibility is to be really big problem to them. As you know majority of the health centers are being managed by the Catholic judge and the government of Uganda.

[00:27:57] So you as the government you're criminalizing them and yet the Catholics are also not welcoming them. Where do you want to go. Where do you want them to go. So it's a big problem but they are all people.

[00:28:09] They need all the interventions that we also get it's a big challenge in my country.

[00:28:16] Those are just my. I've known you for a really long time and I'm amazed at the amazing work that I've seen you do over the years in your community. You're incredible. Your YouTube videos your twerking everything you have done such amazing things. Trying to educate your community and that's what this is really all about is just getting rid of these myths and getting rid of all this bad information and these bad beliefs. Okay so your country in Africa needs 500 super chargers a thousand super chargers 5000 super chargers 10000 super chargers and you're not there. So I'm wondering if there's some way that you could get funding or support to take more advantage of media and YouTube and all that and your fabulous videos that I've seen you do on the star trial and all of that to really try and just really focus in on these cure horrible things you're telling us about. I hope that can happen. Keep doing the work you're doing your fabulous. But I'd like to see ten thousand super chargers in Africa doing what you're doing.

[00:29:18] Yeah. Thank you so much.

[00:29:20] And that's my dream microdot.

[00:29:22] That's my dream. As I told you in the next 15 years I will not be with the energy that I have now. I want young supercharged jazz and I'm glad to report to you that in 2017 I won the VC fellowship for 2017 and my project. There's only to us for one year but my project I told them I want community to get involved into the ongoing cure research. I want to create a network of advocates in my country to empower them about a cure research. So they funded me for some meetings for one year. But the challenge was that I had to interact with only folks around the central and then. The fellowship ended its one year but I'm praying that maybe in future somebody else will come and find these meetings so that we can get more. So party ideas as you say and I'm also glad that I've lobbied I is I guess because of my lobbying I exercise I agreed to organize an HIV Cure Advocacy meeting for the community of Africa every year. I'm the first meeting happened in my country last year and this year's meeting is happening in Botswana. But the membership they're doing a very good job. They get 30 advocates Academy. We need like 150. Every academic. But they don't how fine but it's better than. Nothing. Yeah. Show one more sign.

[00:30:56] I'm Carol. For 19 years. I was part of a group of people who took unused unneeded HIV medications antiretrovirals antibiotics and got them to providers in Uganda and other countries Ethiopia Sudan Somalia Cuba. We need super chargers in this country because it's a shame in this country that now we have beans in our pharmacies where people in their short sighted conservative ways take their unused medications and put them in a bin to throw out when there are millions of people across the world and in Africa who could use them one clinic in Kenya said over the 11 years he got medication we donated five million dollars worth of antiretrovirals that would have been thrown out. So we need super chargers like you in this country to recognize the rest of the world needs what we are throwing away.

[00:32:00] I agree with you. Thank you so much. Thank you so much. You. All right.

[00:32:09] All right they asked me how to open this up and one of the things I thought we do everybody comes from a very different perspective around HIV cure and what I'd like to do is start this conversation off with a simple question from your perspective from your individual cherished perspective. Where are we right now with an HIV cure introduce yourself with your name where you live.

[00:32:50] And where you believe we are with an HIV cure Moses you're gonna go last because you just went first.

[00:32:59] So we're a star at the other end.

[00:33:01] And it kind of sucks being you're in a well the first part is easy.

[00:33:10] I'm Reverend Rob Knowles from Oakland California.

[00:33:13] I serve as executive director of AIDS Project the East Bay and along with Jeff I co-chair the impasse cure cab I'm also co chairing the AIDS 2020 local planning group. And where do I think we are with the cure.

[00:33:27] Yeah I have no idea. I'm a community advocate not a researcher. That's your job. But we are too far away from a cure as far as I'm concerned. And I think we are far away from not not only the research part of getting a cure but the community preparation of getting a cure. We're too far away. We're talking about when we get a cure when we haven't been talking to the general population we've been talking about people that we that we think are at most that that would most benefit from a cure that are actually thinking about HIV on a regular basis. But we're not talking to the folks that don't think about their HIV on a daily basis.

[00:34:06] And so I think that's why we're too far away from a cure.

[00:34:12] Thanks Rob. My name's Jeff Taylor I'm from Palm Springs California and I'm with Rob I'm on the Empire cab as well as a care collaborator cab at the University of North Carolina. And I think it's nineteen eighty seven.

[00:34:24] It really is.

[00:34:25] We're very very early days there's a glimmer of hope just like AZT helps a few people for a little while but we're a long ways away from you know a magical cocktail that's going to stop this disease and we're seeing trials.

[00:34:39] It's encouraging that are putting the approaches together so these cocktails I call them kitchen sink combinations they just kind of throw things together in the hope that something will something will work.

[00:34:49] But I mean that's really where we are right now. We've got one unicorn Timothy Brown who can prove that it's possible so he gives us hope. But yeah it's it's 1987.

[00:34:59] We've got a long ways to go and as Moses was saying you know we need to be wrapping up our activism we need another act up to make sure that we get to that finish line I'm legit now.

[00:35:11] Jeff thanks. My name is Danielle Campbell and I am a member of the extremist activist coalition. I'm also here with the Dair collaborator Ari. I guess sort of continuing in a thread of truth telling. On today's panel I believe in the science and the directionality of the smartest people on the planet to push us and propel us to a space of cure. But I believe that we are not as far as we need to be in terms of social justice and health equity. I think there are large swaths of folks who are missing from cure conversations and I would challenge you all to challenge yourself to figure out why that is. Is it something that's historically accidental or is it something that is intentional and just sort of corralling some of the prevailing themes of Liz Barr's talk this morning about where a cure studies are situated around the globe most in the U.S. But when you look at the global epidemic of folks to sort of

bring home what Moses was saying it's in it's on the continent of Africa. So when we look at the disparities as to where cure studies are happening for a wide variety of scientific political and economic reasons we really need to bring home the concept. Why are certain folks missing from the conversation of cure.

[00:36:27] And that should guide the science moving forward.

[00:36:33] Michael Mortlock known anyway to you. Nicole Yes sir. Hello my name is Tyree Jeffries. I come from the yes people were the oak in each band at the pony nation North Carolina and I had the traditional health program director at the Seattle Indian Health Board. Given the state of the epidemic and the crisis among American and incident of First Americans I can say that I also feel that the cure is is very far off you know mechanism in people who are diagnosed today are diagnosed typically in late stage AIDS very low survival rates in comparison to the rest of the population and our women are three times more likely than white women in the US to contract HIV. So we know about this and so when I think from a traditional health perspective in terms of our our medicine wheel we see one aspect of our wellness and our being is physical and everything I heard today has to do with the research on how to physically cure HIV as well. We have to keep in mind too for when we think about non-response to certain populations which I hear echoed over here too. That's a weaponized response that's systemic violence and will we see racism contributing to these things. I think we have to understand that even if that cure arrived tomorrow in a physical aspect we have to do work around the social emotional the community and cultural wellness as well and we don't have to wait for the physical cure to be working on those things. But that won't happen and in this type of situation where we have extreme examples of systemic violence and racism.

[00:38:07] Thank you.

[00:38:14] My name is Tricia Ariza. Defeat HIV cap member and I don't really have much to add to all that. I was all really spot on. But I would quickly add that again the state iterate with the folks up here said that Yeah when we're talking about HIV cure that we are talking about people right for reform for foremost and that those are the conversations that I want to be involved in and that there's a lot that we need to do as community before people participate and are willing to participate in these clinical HIV related cure research trials Hi I'm Laurie Selah.

[00:38:54] I live here in the Seattle area. I am on the defeat HIV community advisory board and I'm also one of their reps to the Martin Delaney collaborate Tree Community Advisory Board and I think we're in a really tricky place with cure in a number of ways. I know when I came home from the first community meeting where they had Timothy and defeat HIV scientists were talking about how they wanted to try to modify and replicate what happened. I was so excited I couldn't shut up for days I would tell anybody who was listening to me about how exciting this was. And as I've gotten more involved the complexity of all of this you know has become much more clear and I hope that call was right today when he talked about this new assay that might actually be able to measure something meaningful about the reservoir because if you don't know what you're measuring it's really hard. You know before we had. A biomarker like via viral load to talk about you know progression of HIV it was

really hard to know stuff and we don't have that kind of a biomarker at this point for knowing how we're doing around cure. And I think we're also in a tricky place because it depending on where you live if you live in a place that has access to one pill a day treatment that has minimal side effects and high efficacy and low barriers to becoming resistant and you have a guaranteed supply and a way to have your meds paid for to ask people that are in that situation where you can take a pill a day that's no more difficult but not much more difficult than a vitamin and be healthy.

[00:40:37] How do we ask people to submit to some of the risks involved in some of the the things that we're doing around HIV treatment. On the one hand you know on the other hand we know that that is not universally available and we need to shift something to make something more accessible and more feasible to people over the long run and a cure would do so much around that. And we know a cure would do something around stigma. So there's a lot of hope involved. And I think we have no way of knowing when the next breakthrough is coming. So in the beginning we couldn't have imagined AZT and then we couldn't have imagined you know combo art and now we're talking about long acting injectables and so the fact that we can't see it today doesn't necessarily mean that we're far away. And so I think we need to have you know committed resources and vision and the sharing of information and really bringing the brightest minds together and I think that there are a lot of attempts to do that which really make a difference in where we are with cure.

[00:41:42] And there was something else I wanted to say and I forgot. So if I think of it I will share that later. But I think we are in it. Oh I know what it was. I think it is really important that we be inclusive and look at who is involved in a conversation who's being included in trials who is conducting trials. I think if we look at the demographics of the people who are conducting trials they're not going to be very reflective of who's who we need to have in the trials. And we have to balance that with people not wanting to be guinea pigs. So yes we want to be inclusive and we also want people to have the right to say well no I don't want to be the first human in which you do that. So I think there's some trickiness and some finessing and we really have to be in dialogue and listening to each other around different perspectives around you know where we can go and what the directions are and the best ways to do that.

[00:42:39] Thank you. Thank you so much. Moses supercharger. Like I said I have so much hope in the cure. We just need to have to keep our heads high just keep doing what we do.

[00:42:55] But I really believe in empowering our community we need to move with our community together. Just imagine if you get the cure tomorrow you'll have a problem with Africa like you are having right now with at the major reasons why we are having challenges in Africa. Because we were not involved in the art at the beginning at the very beginning when it was being when it was being discovered Africa the community was not involved. They just brought it later on. So that's why there are so many adherents challenges accessibility every acceptability everything. So my ADD is that with a cue I need to start involving community right now by breaking down the hard science of cure. We need to start break down the hard science so that they can understand what we are talking about. When you talk about gene therapy resolve.

[00:43:54] How can you break it down into a simple language understood by an ordinary person in Africa. I mean that's what we need to start with. When you talk about the cure I think well thank you.

[00:44:08] I thank you all for for your for opening comments but I want to kind of take us a little bit left and bring us back a little bit right. Right.

[00:44:17] Because I want to take us to U equals U right.

[00:44:21] I want to talk about the role that you equals U plays in a cure.

[00:44:29] And we started talking about it a little bit earlier but then we got off of it and I think that there is a place where kind of the U equals U and I want to call it a movement. I want to call it the U equals U movement in its relationship to the HIV cure science HIV cure research where they chose to cross the plane. Where is U equals U A intervention vs. whereas you equal you cure related Where is it not. How are they related how did they overlap how do you see them how did they how are they the same and how are they different how they.

[00:45:12] Community engagement activities and how is it science and talk to me about you equals you versus cure research and community you know I think the U equals U contributes in some ways to hesitancy around participation in in some in some trials because I think what's happening is we're doing a better job of getting that message out stay on your meds be doubly suppressed and then you won't transmit the virus to anybody and that is a really important message to give people so then if you start talking to people about trials with treatment interruptions people saying well wait wait a minute you know my doctor told me I have to take my meds all the time and people have gotten that message and internalized that message and it's good that they have and it's it's important not only for U equals U but for for maintaining your health and then we're saying and here's a study and you might go off your meds and if you do you might become an undetectable and we don't know when and if you're going to become undetectable but it's like I mean you know detectable again not undetectable and you know I think what we really need are you know home testing kits so that I could monitor myself at home every day and say oh do I have viral rebound if I'm on a treatment interruption and then I don't have to be burdened and go to a clinic and that may and then I could have more more knowledge and more power am I still undetectable.

[00:46:45] So I think we need to think about what kind of technology can there be in place that people can continue to know they're undetectable and then I think we need to have informed consent and conversations with people that that are in trials about the fact that they may become infectious again if they're in a study that includes a treatment interruption. Now if you don't have a treatment interruption you know then likely you would still remain undetectable so it becomes I think less of an issue in trials that don't include treatment interruption. So I think there's definitely impact.

[00:47:27] Personally I think the relationship between U equals you is when you look at all the studies the cure is the cure is such studies you're all getting somebody who is undetectable they're all looking at somebody who will be treated undetectable then given a cure intervention. So the relationship is

that you will have to be undetectable you need to be undetectable. This program we have started receiving it in Africa. They you echo you. It's really very important the science is correct is right. But the challenge we have in Africa we are receiving it in pieces. People are not getting the right information the information that is in Grant is that the minute you are on a out of these you don't pass the virus but the science is you must be on treatment take it correctly be undetectable you must be undetectable.

[00:48:30] So I think that is the relationship between Cure and Joy because you is being undetectable so I bring a whole lot of my cousins to this work with me and I have a whole lot of cousins that have lots of different opinions but a group of my cousins honestly believes that there's already a cure right. I'm doing right and if there's already a cure then you're just trying to get this unique. You're trying to keep me on meds to get money. It's all about them. It's follow the money right. I have a set of cousins that really believes there's a cure and HIV medications are for profit only. And then have some other cousins that find themselves a little more savvy and they say we've all yelp been telling me we've already got the tools to end the epidemic in this country. We've got prep and we've got treatments prevention. We don't need anything else why are you still experimenting on folks. Right. Because there's medical mistrust which is real which we gloss over quite a bit and never really address. And we wonder why black folks aren't in our studies because we have not addressed the medical mistrust. And so you lose you in relation to cure research is why should I be in a study.

[00:49:36] If we've got what we need.

[00:49:41] Yeah I was going to try. Come on out there. But I think Rob sort of hit the overarching theme of what I wanted to cover but I think you know you equals you is a great great public health message and I don't think is being marketed as such. The HIV folks have own that message. And we've not disseminated it to other public health communities that can benefit from the advocacy arm of of how effective it's been at reaching the world is shifting the paradigm when we talk about sex positivity and disease transmission. Right. But I think just as a woman who does work where the rubber meets the road there's this lack of translate ability when you look at African-American or black folks when you look at women when you look at the treatment cascades and you go talk you go down the 1990 90 black folks are more likely to be diagnosed less likely to be virally suppressed less likely to be in situations socio economically where they are contending with their HIV diagnosis on a day to day basis tell you you equals you is great but in certain populations you'll miss the boat each time because they have so many other social factors that get them to a place of acceptance before you talk about them being virally suppressed and the message isn't that your. There's almost zero risk of transmitting HIV to your partner. The message should be that for how long you need to be virally suppressed. Right. Because if you're already talking to folks who aren't virally suppressed then the message gets skewed. Well I'm just gonna get undetectable and then I can't pass it to my partner. So we still have a work to do around the dissemination messaging of you equals you in this you know fantabulous public health messaging campaign. So I believe in it. But again I think just as someone was representative of a racial ethnic demographic that is often missed and overrepresented in this epidemic remember that again.

[00:51:42] One thing that I think of is that you because you is not even reaching American and in communities in fact we're still trying to raise awareness that people need to get tested and if you think about Indian Health Service it's funded at about 50 percent of need. And so there's barriers there. And then the historical barriers to even accessing care comfort of going to seek a Metro medical professional. We think about the era of eugenics for American Indians it ended very recently. And so there's still a lot of distrust of medical establishment. So I think the mountain is really steep for getting that information out there.

[00:52:15] So whether or not this is you know that conversation of you because you and cure we're not even having that conversation we're not at that table so I guess it's one of the things you know I serve on the believe kid and that's one of those things of you know I've done HIV vaccine work and I've been involved in HIV vaccine work HIV cure research. And you know I you know we don't see a lot of people of color researchers and scientists in this in this work. I think we look at the WHO are the participants in HIV cure research it's a low end in most of the studies as it is.

[00:53:02] And they are older and I think that there is some level of altruism there. I think it's older white guys are willing to take this risk.

[00:53:12] You know I mean why is that. Why is it that older white guys are like OK you know I guess I mean why is it. I mean why do you think older what I'm looking at you. Jeff

[00:53:24] Good for you. Long enough. I could look at you and say hey old white guy. Yeah well in Palm Springs go on. OK.

[00:53:38] All white guys never die. They just moved to Palm Springs. So I think part of it is historical. The disease was first recognized in the in the gay community and not just the way I mean overwhelmingly white but I mean we need to acknowledge that you know everybody anybody can be gay but I think historically they were the ones and it was a result I think of the political climate at the time that's when the gay community was first finding its political voice and suddenly AIDS hit it and hit it hard. And that's why people turned to that political activity towards AIDS. I think it's a real historical coincidence. I don't think there's anything I'm

[00:54:13] Sure I'm asking HIV cure specific. Yeah right.

[00:54:16] Because this is this is like this is I think it's there is like there's an anomaly where we see an HIV cure. It's really white. And it's really male. Yeah.

[00:54:27] So there are a number of reasons for that. I mean the reason I was kind of going back into the history is because they got involved in research. They're really invested in research. That's why we're alive. I think in the gay community people recognize that. So that's where that altruism that you're talking about comes from from that older generation. You talk to the younger millennials and they're like maybe I don't want to do this.

[00:54:45] I've got a life to lead you know a job and bills to pay. So I think that's historically why we got there. But in terms I mean a lot of it is just all the social and economic injustices that we live with in this country. Right. That sadly white people hold most of the power the education and access to the funding and that's how it gets there. And that translates into you know the people doing the research are going to the most to turn that around. People looking to participate in research can be most comfortable doing that research with people who look and feel like talk like them. So I think that's true in any community right. So I think that's that's why that's that's happened and it's not a good thing. And some of us from beating the drum for years saying we have underrepresented populations. This is not a gay white male epidemic anymore it's completely shifted. We've been trying for decades to get more women involved or people of color involved in studies and there's all these structural obstacles to that in terms of you know having clinics in the right place having clinics in the communities where people need them having providers who are of that community so they can build that trust the medical mistrust that Rob was referring to and just making it physically easier. So people how jobs can go on weekends and evenings and just because there's limited money it's always a deciding factor. Nobody wants to put in the extra time and money to make that happen.

[00:56:10] And until we stand up and say you have to it's not going to happen.

[00:56:16] We have like ten minutes left. So I want to make sure people do. Let me just add.

[00:56:20] Let me just add for that. I think we don't see more particularly gay black men participating in cure studies a because most of the studies are in the United States and I think you know most of the days when you see more black men in studies right. But where the altruism isn't as strong I think because we don't see the epidemic like why gay men saw it in the 80s and we don't see we're not as connected to our brothers and sisters on the continent of Africa. I think if we were as connected to our African roots then there would be more altruism in African-American men and women to participate in studies. I'm going to take my readers liberty and ask my brother from another mother who read it with the last question Cornelius said you after they. Got

[00:57:15] Done Vega's here.

[00:57:24] Well no I mean but see I think this is a really good question and a good point but first I want to go back to this last one. Oh hi I'm Cornelius Baker from Washington D.C.. But first I want to just go back to this other question about the participation of communities particularly black gay men. And I want to just really remind us that it was just what eight years ago nine years ago that the HIV vaccine. I mean HIV prevention trials network did its first study looking at HIV and black gay men. And I want to remind us that that study HP t in 0 6 1 was a feasibility study because what the researchers said was that they didn't know whether black gay men would even participate in research that trials showed that black gay men would participate in research. It was fully enrolled. The carryover was all 73 looking at whether black gay men would utilize prep. That study showed that black gay men not only would utilize prep but I had a ninety three percent retention rate. There is currently no study in any of the networks or CFR it's looking specifically at gay black men. So before speaking about whether they will participate in any form of research maybe we should hold the

investigators accountable for looking at where one quarter of the epidemic is in the United States though.

[00:59:03] But then once you move on from that I mean I'm. I mean you meant you. I think that the question you just asked is a really important question because you asked me where is the cure research. I have no idea and I mean you know and I think that is not to be arrogant but for all of our communities we've got to figure out a way to get this easier to our communities and to the one point two million people living with HIV in the United States but also the other 35 billion around the world. But if in the United States would all of our media channels and all of our organizations we haven't figured out a way to inspire ourselves to be interested in a cure or I think we have a problem and I think that we have that and that's why I actually came here today. I mean this morning and I could I had other stop but I wanted to know for myself like how do we do this better. And I think that this is a really important question. And I just want to just think people for putting this together because it's been enormously helpful to me. But I think it reflects the work that we have had

[01:00:24] As so any last minute comments because I have to wrap up before Michael kicks me again. Now. I want to thank everybody. I want to thank our panelists.

[01:00:39] I love you all. I know you may not always feel that love come from me. But I do love you all thank you very much.

[01:00:50] Y'all can stay right there if you want don't worry about it.

[01:00:52] So we just have one last piece of business and that involves Mr. Timothy Ray Brown. So let's see here. If I can't talk and you want to pull those up one version if you want to do the Stevie Wonder you're gonna lead it.

[01:01:06] You got it right. Yeah. We're gonna play this first. So Timothy why did you come up here so as you've heard numerous times here.

[01:01:14] It's the twelfth cure birthday for Timothy and I just wanted to kind of go through a little bit of history about how I started doing this because I was really kind of funny. Let's go back to not just the video to my slides where the

[01:01:32] Kind of got them. I think you can see them there. Yep that's the do we not pull the right ones.

[01:01:39] I thought it was a t RB there that's 20th birthday. You got it.

[01:01:43] There it is. Ha ha. And I can click on here for this. Okay. Cool.

[01:01:50] So you know basically how did I learn about the date of his transplants that cured him of HIV.

[01:01:58] Well it was actually at a click click which click on my click and here to do it arrow arrows arrow. Well there we go.

[01:02:07] So it was actually a gay part pride here in 2013. The advocates here locally managed to get Timothy not only into the parade but we got him onto the stage at Seattle Center and they kind of surprised me at the last minute and said You're going to introduce him. And I was like Oh my God what am I going to say what am I going to say what am I going to say and then so the last thing that was I was like Hey Timothy what was the date of your transplant. And he told me. And so I went out there and I said to everybody your lives all changed on February 7th 2007 and you don't know it yet.

[01:02:38] And that's how I introduced the idea of someone being cured of HIV and then let Timothy talk for about 10 minutes on that stage. If you don't know one of the things that is interesting about Seattle's ties with all of this is that the bone marrow stem cell transplants were sort of refined and perfected through e Donald Thomas and his work at Fred Hutch and he won the Nobel Prize for that. So it kind of brought this home that the first HIV cure came from these cures of leukemia and other incurable cancers that have resulted from that. So here we have sort of a family tree of cures that we have done and Daddy there in the background with their bone marrow stem cell transplant. And then we had Garrow who are here in 2015 with Timothy and we got them all together to show the sort of lineage. So if we're going to celebrate HIV cures here's our family tree to begin with. But one of the things that I learned from learning about bone marrow stem cell transplants let me go back is that people who survived their transplant treat that date as a second birthday. Some of them call it a rebirth day or a happy BMT birthday. And I thought maybe we should do that for Timothy but one of the things that Fred Hutch did was pull a bunch of the survivors for a bone marrow transplant reunion in 2015. And I was really sort of moved by how many people were willing to have their picture taken to be shown as a survivor. And then it also got me thinking to some of the other things that have been happening in the news where people believe that Timothy's was cured maybe but now he's no longer cured it came back and you can see even in the news there was some speculation around that and a lot of people have heard they would tell me that they heard that Timothy was cured. But oh it's come back. But Magic Johnson is still cured. So it seemed like there was a lot of confusion about who is cured and what.

[01:04:18] And I thought What can I do about this and so my bright idea was to take that birthday idea and start marking the years and doing it as a way of teaching people the actual date of his transplant because as I learned from Garo hooter he was transplanted on February 7th 2007 and 68 days later much quicker than they ever anticipated. They could find no more replicating HIV in his blood his HIV DNA. It didn't exist anymore in 68 days. So the seventh birthday came up that year and that was in 2014 and at a cab meeting we beamed Timothy in and we kind of sang to him and eat some cake on his behalf. And then when we were here you didn't get any of that you know we couldn't virtually send it but he did get some of the next year with the eighth birthday. We actually did that here at the library in 2015 when I flew Garo hooter over to talk here with Timothy and appear publicly together. So that was one of the blessings of the 8th. And then again we did a ninth birthday which was just our cab

once again but then that led to 2017 when I realized Oh my God it's gonna be 10 years and ten years seems to be a big big sort of anniversary.

[01:05:23] And so I got Fred Hutch communications team to really sort of wrap their heads around this and help us promote the tenth birthday of Timothy's cure. And what was really beautiful in that article Timothy says something about being the lonely club of one person cured and all these bone marrow transplant recipients wrote in in the comments section and I can only give you some of it. He's not alone. He's not alone. And they just were all listing their birthdays and telling him good wishes. And it was one of those sort of very emotional things for me to read all of that positivity especially because on Facebook comments there's usually a lack of positivity. So it was just really touching thing to see and so we actually did celebrate at the 2017 HIV queer research birthday we celebrate it. We ended with a tenth birthday celebration we had a nice cake. We sang to him and we even then sort of succeeded in getting that out into the press. So people who were there who write for other magazines started to repeat it. So it was a way for us to announce to the world. Ten years cured and still cured. And it's been ever since we've been doing that. So last year was his 11th birthday and we had a cap meeting on his day.

[01:06:31] And so we're not gonna be able to play this or not maybe we'll just skip over it.

[01:06:35] How do we get this here. Palu maybe maybe not. Anyway maybe you've been spared hearing it. Know it's really just me. It doesn't like it. We're going to skip it that's fine. It doesn't matter. So eleventh and then 12th I did.

[01:06:51] This is a post on February 7th 2007. I also texted Timothy to remind him that it was his birthday and I figured since I was sort of attacking him in these posts that he might be aware of it. So he could be ready for the onslaught. And indeed there was an onslaught but you can kind of see it wasn't just people with positive wishes. There were a lot of people who still have not gotten the word that he has been cured. You can see that stop misleading us. I'm not so sure of it. What's the real story. And you know I don't think you are the world then if they cured one person. So there's a distinct lack of understanding and even then the people who understand are expressing some sort of pessimism. In other words it's been 12 years and people see that as a way too long. Why don't we have other cures now why don't we have other people like this which we'll find out the reason why. But I really realize how important doing this 12th birthday is and so what I wanted to do is have us all come together and we're going to actually sing Happy Birthday to him so why don't you take the center here. Timothy and do you want to sing to Stevie Wonder version for us

[01:07:51] All right. I don't know why

[01:07:54] You feel all right you ready. All right.

[01:07:58] Ready. Happy birthday to you Happy birthday to you. We're doing this Stevie Wonder version. Happy birthday to you Happy birthday to you happy

[01:08:17] Day. That's it.

[01:08:19] See you at 3.

[01:08:31] Happy birthday to you Happy birthday to you Happy birthday.

[01:08:44] Happy birthday to you.

[01:08:53] Thank you very much for coming.

[01:08:55] We have cupcakes for you all to enjoy since we don't have enough cake. You have the money. So if you please stick around. Have some coffee and have a cupcake. We'll be serving them up. But thank you very much for a very successful day. I hope you all learned a little bit and feel fired up to do more to see if you home one day. Thank you

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