Medical Angels

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[00:00:36] Thank you so much for coming out tonight. My name is Misha Stone. I'm a librarian here in the Reader Services Department. We are honored tonight to be doing this event with defeatHIV. And the library is always honored to be working with community and convening community in the ways that they want to learn and grow and celebrate. So thank you so much for hosting this event with us here. I want to thank the Seattle Public Library Foundation that makes so many of our free library programs possible. I want to pass this over to our planner extraordinaire, Michael Louella from defeatHIV. Thank you.

[00:01:16] And thank you all for showing up tonight. Before we get started, I just wanted to acknowledge that we are on the traditional lands of the first people here, the Duwamish people, both the past and the present. And I want to honor with gratitude. The land itself that we are on and the Duwamish tribe. Let's keep them in our hearts when we think about these things. So we're here tonight for this event called Medical Angels. And it was one of those names that sort of struck me a while back when I was first forming the idea for this. And I'm so used to saying medical heroes. When we talk about people who participate in clinical trials, especially when they're doing something that's beyond themselves, they're not getting any sort of personal benefit. But it's sort of made me realize the sort of legacy that there is around HIV and participating in trials and the people who participated in those trials in the late 80s and early 90s who helped us create antiretroviral therapy and get to the point today where some people who are newly infected could go on a one pill a day and not have any sort of severe side effects. And it's all because of those people who were getting involved back then. And as I was putting this event together on Facebook, people would write little comments. And there was this one individual who just wrote this comment and it just touched me. It was my oldest brother was in a 20 year study in the early 80s at the College of Berkeley in California.

[00:02:37] And he's in heaven now. But because of his participation, he helped save lives. And I wanted to thank everyone involved in studies now. And I just thought that sort of thing was really the spirit behind this. We're all medical angels in some ways, no matter how you get involved. And now that we're trying to cure HIV or create some sort of long term term durable control, it's going to take a bunch of angels. And so I guess I grew up in the 90s where Angels in America was always in the back of my mind. And so medical angels is what we're calling today. This is going to be a conversation led by the community. So we have our three community people on the left side and we have our three honored guests and I'm going to let them introduce themselves to you all. We will have a few rounds of questions that they'll start us off to get us behind the story. You also have the story in the program and you'll see some slides back there that'll be filling you with all sorts of ideas. And but we're then going to turn the microphones loose and it's really going to be your forum. So the questions that you want to ask, I should let you know that this idea came up as a result of some of the community based participatory research that the defeatHIV CAB helped do with defeat HIV collaboratively.

[00:03:46] We did some focus groups about the acceptability of a cell and gene therapy approach to curing HIV. And we got a lot of feedback from those individuals and those focus groups. But one of the things they wanted. They wanted to hear from people who went through these trials. They wanted to hear from people what it was like to do it. And so I took that to heart. And that's where this event really came from. It came from that focus group and those ideas where people wanted to hear from the people who have done the trials, what it was like. And so this is sort of trying to sort of close that loop and bring it all back. This event is going to be recorded. It will be recorded by the Seattle Channel. And it's also being live streamed on our Facebook page. And so if you're on Facebook. Hello and you can write some questions in the comments section, and if we can get to those, we'll bring those up as well. So hopefully we will have a long lasting document. So those people who wanted to hear about what it was like to be in those trials and what it's like to take these interventions will actually be able to get an answer one day if they find the videos. All right. So I'm done talking. Thank you very much. And I'll turn it over to you all.

[00:04:53] Hello, everyone. My name is Manuel. I am a defeatHIV Community Advisory Board Member. I'm a young person living with HIV. I have been living with HIV for the last seven years.

[00:05:06] Hello, everyone. My name is Tranisha Arzah. I've been living HIV my entire life. Twenty nine years now and I'm also a defeatHIV Community Advisory Board Member. My formerly worked out a program called Babes Not Work, which is a peer led women led program that provides services for women, including trans women who were living HIV in their families. And currently I work as an HIV/STI Tester at Gay City, which is Seattle's LGBTQ Center.

[00:05:35] I'm DeAunte' it sounds like Beyonce, but I sing better. I actually am a Peer Navigator for POCAAN which is known as the People of Color Against Aids Network. It's been around for almost 30 years advocating for people of color within our community. I'm also the NAACP first LGBTQ Chair. And within that space I want to make sure that if we're going to talk about the advancement of our space, we have to talk about HIV.

[00:06:01] When it comes to our LGBTQ community and I'm really happy to be here as well and our other panelists.

[00:06:09] Hi, I'm Carl June from Philadelphia at the University of Pennsylvania. For about 25 years, I've been working on cell and gene therapy with CAR T cells for HIV.

[00:06:20] Hopefully we'll get to talk more about that, Lou. First of all, I want to say it's an honor to be here. And thank you, Michael, for all your work. And thank you for the researchers for your work as well. My name is Matt Chappelle. I currently live in San Francisco. I had HIV nearly my entire adult life. I'm a former actor, Golden Gate member. I've done quite a bit of activism and quite a bit of participation in community advisory boards. I was one of the. I was asked to be here because I was one of the people that participated in a gene editing study. And I'd been off meds for five and a half years with a viral load average of one hundred.

[00:07:03] Hi, everybody. Matt Sharp. I'm from Berkeley or I live in Berkeley, California, right now. I'm originally from Amarillo, Texas. I usually don't say that, but it's great to be here. I always feel so comfortable coming back to Seattle. And I just want to thank everybody at Fred Hutch and Michael and everybody who is so gracious for me to come here every time that I ask and want to be here and join you and learn. That's what I do here, is learn a lot. I was diagnosed in 1988 and I'm 63 years old. I'm a long term survivor. I guess the reason I'm here tonight and many may have heard or read about my story is with the gene editing trial and saying amazing zinc finger. And I'm going to talk a little bit about some of the positive results, some of that really results that weren't expected from this trial that I saw. And in my case and in many people's cases, I'll just finish by saying I follow really working.

[00:08:06] Now, my main focus of work is, is mobilizing long term survivors and people that are aging with HIV across the country and work with a project called the Reunion Project. And we were here in Seattle actually two years ago.

[00:08:21] Thank you guys very much. So I actually wanted to take that before we start talking about the gene therapy. I wanted to actually go back to you guys as individuals. What was life like before the diagnosis? Who were you? Where were you at?

[00:08:35] Sorry, I feel like Oprah right now. So if you guys got to give me a question.

[00:08:40] I was a little busy just just saying in the 80s, I'm one of those I.V. drug users that you think are never gonna get sober and ended up homeless in San Francisco. I was a little busy. It was no surprise at all to me. Actually, I knew about I knew I was HIV positive when I lived in the state of Michigan, which has draconian reporting laws in the 80s. And there was absolutely nothing they offered you except for surveillance. You get calls from the Health Department all the time. It really sucked and I left. So before I learned that I had HIV. Yeah, I was just a drug addict.

[00:09:21] Thanks for asking that question.

[00:09:22] It's a question that doesn't get asked a lot, and I really appreciate it personally, but so I was a ballet dancer. I was in the middle of the very middle of a 25 year ballet career.

[00:09:34] Actually, it was a 15 year ballet career added 10 years to and I came down and I got a test for HIV and started watching my community die around me like one at a time. And.

[00:09:48] And I fell into it. I just immediately said, I'm not going to I'm not going to die from HIV. I'll get hit by a bus first. And maybe that's why I'm still here. Just make sure when we leave tonight that a bus doesn't come around the corner.

[00:10:05] Dr. Carl? Well, where were you at before this epidemic hit as well?

[00:10:11] So, you know, I had a I actually trained here in Seattle in the 1980s in bone marrow transplant, and that was the first cure for leukemia. And when you look at it. Cancer in some ways. When you get a diagnosis, it changes on a dime. The same thing happens like, you know what you just heard from the Matts. So the whole life change. And so I started here because I wanted to work on the immune system. And at the time, in the early 1980s, the worst immunodeficiency was bone marrow transplant because it took away your immune

system with radiation and chemotherapy. Then AIDS happened. And I started working on that. And in our first CAR T cell trials started in 1996, we began a lot of people don't know that they think mean CAR T cells are now marketed, you know, for leukemia. But the first patients ever treated actually had HIV. And we did that then when there were no drugs. And it was just an awful carnage. And then, you know, the drugs came out and the industry didn't care about making something for HIV. And then it went to cancer. But so I I have gone through this circle of from working on HIV to cancer and HIV.

[00:11:25] I also wanted to add that when I got my HIV diagnosis, so it really felt like I got a whole disease of society with a virus. Like you get all the stigma and everything else that goes with a virus, no matter who you are, what you do, it follows you. And that was like the most profound thing with finding out that I had HIV.

[00:11:45] Great, thank you. So let's get a little more background before the Sycamore Trial. The Matts, have you all participated in any clinical research trials prior to this one? If so, what were some of those trials? What were the processes like? Were they similar processes to the one that we are wanting to dig more deeper into?

[00:12:05] So Matt and I were talking about this on the plane ride over. Matt lives in San Francisco. I live in Berkeley. So we got to travel together. We actually I want to just say we know each other from we were an Act Up Golden Gate together and shared many strategies about how to get arrested and how to get attention. Anyway, I have been in so many clinical trials that I lost count. I really I don't I don't I try to somebody try to help me figure that out. I have it all filed away in boxes.

[00:12:36] You know, my reports from some of the trials. I just don't I can't remember them all. But I was in some of the first AIDS clinical trial group studies.

[00:12:45] I was in [inaudible] the first combination study at Stanford, by the way. Anyway, millions of studies for pills.

[00:12:55] And then because I started that down that road, I developed multi drug resistance as a result. As you all heard the story of sort of this recipe for disaster that a lot of us went down, which was, you know, we were desperate to try anything we could could get our hands on to save our lives. So we took the latest pill that came out, adding that to a virus that was already vulnerable and ready to escape around the new drug inside. Eventually what happened is I developed multidrug resistance and started looking for immune based therapies.

What a concept. Why don't we figure out something to to change the body rather than the virus? And we developed a whole Matt was a part of it with Martin Delaney from Project Inform to push for immune based therapies. And so one of the trials I was telling Matt about, you know, that you talk more about your study experience was I was involved in Dick Hong's thymus transplant study, which Carl knows about. I flew halfway across it all across the country to Vermont to have a thymus transplant. And I'm not going to go into the detail. It doesn't sound as gory as it was, but it was very risky. I had a plant put in there of a child's thymus. This is these were babies that were born that had heart problems and they had their thymus tissue removed at birth. And normally that tissue was just discarded. So Dick Hong, was this a brilliant researcher in Vermont who thought, well, maybe if we could take that thymus which is really viable immune tissue, put it in the people with HIV, maybe it would restore some immune function.

[00:14:47] We did the process.

[00:14:50] We went through taking horse globulin to make us so we wouldn't become immune to the thymus tissue that was not our own tissue. This foreign tissue, everything was safe. Everything was fine. Except guess what came along during the surgeries, heart therapy.

[00:15:08] So heart therapy got to the main stage. And the research on that whole era of thymus research stopped. The good news was it was safe and the tissue that was put into my body from another from a baby was viable tissue. But that's all we know about it.

[00:15:27] What is heart therapy for folks that might now know? Heart therapy, highly active antiretroviral therapy. It's typically not call that anymore because all the therapies we use now are highly active.

[00:15:39] But at the time it was a cocktail of two or three more drugs that were highly effective.

[00:15:46] Just for those who don't know, the thymus is where you make T cells and it goes away usually after adolescence. So that's where you have a hard time making new T cells. And that's why the idea was tried to see if you could make it like a baby again and make a new immune system.

[00:16:02] And can I just add one thing about, you know, I'm so fortunate that I was in a community in a setting where I could learn all of this stuff that made me want to be a part of it. Normally, I wouldn't know. I wouldn't have ever jumped into a study like that. But I was immersed into all of that activism so heavily that I saw that possibility and someone invited me to it to be in the study, probably because I was part of the Immune Restoration Think Tank, which is a Martin Delaney's thing. And I signed up. And who knew? You know, maybe that's why I'm still alive today.

[00:16:35] Thank you.

[00:16:37] It's really tough act to follow. He's not telling you all of the studies that he was in. So I think there's a couple things. One, there's how I like. When I moved to San Francisco in the late 80s, it was like moving into a war zone. And I became very angry and in my tendency was to self-destruct with anger. So I focused on doing something, even if it would be a failure. To me, it would be more important to try and fail than to not try and fail. And so somehow in our Act Up in San Francisco, we had a treatment issues committee that really just studied immunology and we had read textbooks and things all the time and talk with researchers all the time. But really what we did is we like like this yourselves here is to make research happen. And I think the thing about research that I just want to be clear about my own motivation behind it. I never really had the motivation that like I'm gonna get some stellar benefit from something because I'd never thought I'd survive this long. It was for future folks that like, well, if you going to answer this question, maybe it'll benefit people down the line because, you know, you're this future generations. And so I really kind of took that perspective about it, that it had really nothing to do with me at all. I did do some desperate things, like we were able to make some medications like DTI, for example, back in the day and get those on the underground.

[00:18:08] And I did take part in those before they were approved. I was fortunate to be in a situation to access that. And that is not something everyone can do. And it's simply because I was involved in activism. You know, I've always had this feeling that when I have access to something someone else doesn't, that, you know, sometimes I feel bad about it because I want everyone to have access to everything. And that's one thing about trials. It doesn't really address social determinants of health, as they say. It doesn't get you food. What it does is, I guess, the simplest way for me to say it is, you know, my perspective is out trials or not treatment trials are trials, you might get a benefit. You might not. That said, I was involved in a lot of community advisory boards, including including the AIDS clinical trials groups. Somehow I ended up doing neurology research. Just leave that alone. We all had our niche. I was told to do that. So I did it. But I was on IRBs and quite, quite a few things. But the whole point of that is my whole motivation was to make research happen and to do whatever it takes to make

research happen. Incidentally, in the state of California, if you have a lot of civil disobedience on your record, it doesn't go away.

[00:19:23] Thank you. Where did that come from?

[00:19:27] So I want to highlight and the materials that we received, there's a little hand out and it talks about the current and future landscape for HIV, talks about this CCR-5 Delta 32 mutation and its global distribution and then the bottom chart is the distribution problem for HIV, the ability to manufacture these genes that we're talking about. And it's globally limited. So as you can see on the bottom chart, it's not only the manufacturing, but also it's overlaid with the current epidemic of HIV. And so as you can see where we are with the clinical trial process of cell and gene therapy on that first chart on the top, we're at the beginning step, the baby step. And so my question for the panelists would be, how often do you think about the occurrence of the natural genetic mutation, given its distribution, not matching with where that epidemic is seen globally?

[00:20:33] So I began working with Sangamo in 2004 for actually and we did the first patient and you heard this from Matt, but our first patient treated in 2009. But the original gene, CCR 5, was discovered because of hemophilia, which a lot of people don't know. Hemophilia, you know, is mostly in boys because it's a sex linked gene. And when the HIV epidemic happened, initially, they didn't have blood test. So the hemophiliacs got blood transfusion all the time. So they got infused I.V. with live HIV. And I was in Philadelphia at Children's Hospital. All the kids with hemophilia got HIV and died, but a few survived. And when they test them later, they found out they had a natural mutation in the gene called CCR 5. And we now know that this occurs and you know about it both, you know, you have two chromosomes. So on both of your copies can be non-functional. And if you have that, you won't get HIV even if you get an I.V. infusion. So and it only occurs in northern Europe. There is. We don't know why it didn't occur in Africa or in Asia. And the thought a lot of people have is it happened because of the plague epidemics in Europe, which were caused by rats and a lot of people died. And that's a really big activation of your immune system. And that may have helped you survive if you happen to have that. So now what we have is it's a marker of people who won't get HIV. And and then now it has been used. Now can we. You know, the cell and gene therapy approaches, can we introduce that into someone who didn't get born with it? So, you know, 10 percent of people have one of their copies out and about 1 percent or 2 percent have both of them, and they're completely resistant. But now you can with cell and gene therapy, you can make that happen to everyone. And that's what the Matts here have had gone through.

[00:22:33] So back up to the late 80s, early 90s is what would happen, a lot that people probably don't know about is you would have researchers that were scared of you because

you show up angry and sometimes researchers, but usually drug companies would try to give you a drug that isn’t accessible to everybody.

[00:22:54] And what would our group really held to is that we don't want things that aren't accessible to everybody. So on one hand, there is there's studies and studies are studies, and not very many people go into studies. I mean, like my thing is that they're there to answer a question. But as far as you know, I guess one way to put it for me is that, you know, activist skills are portable skills. And so you do what you do as an activist. You work on a macro level of things. And for me, what I did is took that to individual level, you know, so so you can take like all those skills and use them hopefully a productive way. But what I don't want is I don't want a treatment that not everyone can get. And I think that the researchers here can answer how complicated that is with something like gene editing. But yes, to me, I think about it actually daily.

[00:23:54] So actually, by going through the therapy throughout those process, you said groups. So what was it like going through with with the therapy? And then do people know that were you in groups with people that you knew that were going through the same therapies process as you and you coming out of that process? How did they feel with you being cured?

[00:24:15] Well, you know, what's interesting is the study I was in. I'll go into detail later, but the way it was set up is that they staggered the folks that were in the study so that you didn't meet other people that were in the study and they were kept their confidentiality very well. But the weird thing about just to digress a little bit about the study that I was in is when you get your cells, you smell like rancid cream corn. So I could figure out by who's in the office, who else got the who must have just got their cells. And so I only knew a couple people that were in the study site that I was at. So we didn't really it, to my knowledge, and Matt might be able to expand this. I don't know all the people. There wasn't really a group, you know, like like I don't know those people. But there's a lot of medical reasons why I wish I did, because I think that overall, globally, those of us that were in the study do much better afterwards because a lot of people were kind of treatment failures all the time. Like myself included quite a bit. I'm going to pass it to Matt.

[00:25:27] I would just add that, you know, would you enter any kind of clinical trial like this? You've signed a bunch of documents, right? Just sort of sign your life away. Not really. But you want to make sure that you're you're protecting your confidentiality. So usually you do that in a private setting with a doctor. And so if you're in a study, the only other person you will know that's in your study is just because you happen to know they're in it and you talk to them. They may be coming to the same clinic, but they may be in another complete study. So you really never know the saying about trial.

[00:26:01] I was actually invited to be into that study by J.

[00:26:04] [inaudible] who runs a clinical setting in San Francisco, who said he approached me and said, would you?

[00:26:12] This is a perfect trial for you at this point in your life. And so that's the only way I knew. And then the other way I knew was after the study was over, people would post stuff like Facebook.

[00:26:24] Right. So you see, these are people who are in the study at that point.

[00:26:29] But that's the only way. I don't keep Facebook.

[00:26:32] I think that's a really interesting segue from, you know, all the HIPPA rules we have to protect confidentiality came because of HIV. But it's had some negative effects. I mean, we don't know. You know, it actually slows down research sometimes, like if you want to do it, like what was done for Tim Brown and give a transplant for someone who has leukemia and give him a bone marrow donor who has the CCR-5 gene that you want. We can't do that in United States because you have to you can do it in Europe. But our HIPPA laws don't allow that. We can't go back without it getting consent from everyone. And where it's been broken is what Matt kind of just hinted at. So in my case, I started treating kids with leukemia and sometimes we had spectacular responses, some not. But the parents started made these Facebook groups and all of sudden, everyone knew who everyone was who was on the trials. So the parents actually learned about the progress faster than the physicians did because you had to wait to get it published in all that. The Facebook has accelerated research in some ways. And it's I'm blinded. So it's a really interesting thing you brought up Matt.

[00:27:46] Thank you. Let's talk about more your experience going through the clinical research trial. What was your experience in the process like for you personally, emotionally, mentally, physically, even? And did anything particularly come up for you that maybe you were taken back by.

[00:28:04] Wow, so much. I mean, at the time I was approached by the investigator of this zinc finger trial. It was a safety study. It was the first. This is right. This was the first gene therapy trial in HIV. Correct? The zinc finger, No.

[00:28:20] The second. Do you want to tell a little bit of the history of that.

[00:28:25] Or one thing is gene therapy is putting in a gene that's called gene transfer. And the first trials and that work with CAR T cells, actually. And we did that with in south San Francisco, where the company is now out of business called Cell Genesis. And so we treated about 40 patients. We actually found it very safe. And that it's actually those patients still now, 25 years later, still have CAR T cells. So we learn a lot from that. What Matt's talking about is gene editing, which has only been possible the last few years, where you can actually find a needle in a haystack and take your own genes and change them how you want them to be. So it's not the addition of a gene, but it's just rewriting the genetic code.

[00:29:10] And I was looking up at as an aside, the first gene therapy and correct me if I'm wrong, the first gene therapy patient died. Actually, it was a J&J ribozyme trial. Is that right?

[00:29:25] There were. So the whole history of gene therapy, I mean, it's complex and complex and and it had some initial Biotech involvement and then Biotech got out of it because they thought it would never become commercialized and it became all academic. And then Sangamo came back in with with with the [inaudible] on because they had gene editing technology. But there are from fits and starts. And then there are some toxicities that made, you know. So the initial trials and they got very highly publicized and everyone got afraid of it. Yeah.

[00:29:59] Thanks, Carl. I think for me, it was my salvage, really. I mean, it was the way I was going to stay alive because I had no I run out of treatment options. As I said before, I'd use every drug class that was available and I kept waiting for the next new drug.

[00:30:16] And I just knew that wasn't going to last me. I just my t cells started falling. Fortunately, fortunately, my viral load was was suppressed at the time. But when I had heard this opportunity of an immune base like immune based therapy, you really I an immune based therapy because it was using my own cells, just manipulating my own DNA that I might have a chance. So I jumped at it. And I honestly, you know, I talked to a lot of these guys, scientists about is this going to be safe for me? Do you think this is something I should try? I didn't go at

it blindly. I certainly did my research. Talk to people. Martin Delaney and the people that knew their stuff.

[00:30:59] And they comforted me enough to know this. You'll probably be OK. And they were probably gambling just by telling you that. Right.

[00:31:06] But I it was it was fine. And the procedure was literally you may be surprised at hearing this. Does everybody know what apheresis or apheresis procedure is where they take your blood out of one arm and they separate it in a machine and they collect for, in this instance, the white blood cells, and then they put the red blood cells back into your body. So you've got these tubes running out of your body. It's about an hour long process, but it's a way for them to collect a large amount of cells and they need those cells in order to manipulate them and to, in fact, they grow them in the laboratory and then they infuse my own, so there are my own cells they infuse them back into my body. So there's really no there's no really chance of me being becoming having an allergic reaction. There's little chance of that happening. I waited about a month. I got a call to show up at the clinic. The product they called it product was this little white bag.

[00:32:10] Looked like it looked like mayonnaise almost. You know a white I.V. bag, it was frozen solid. They had the thaw it out and they infused it into my arm in 20 minutes. That was the only thing I did for this trial, except then later come back for blood draws. And I had something like 12 sigmoid colon snips to test my colon to see if the cells had gotten into my colon. And that was that was not exactly fun, but it was certainly something that I got over and I did because I knew it was, you know, something that hopefully would work for me. And that was it.

[00:32:56] Basically, you know, you're. You're two years later, the results of the study for me were not expected. And for almost everyone, I think in the trial, the CD$ cells doubled. Now, we were all people who had been on antiviral treatment for years, were called immune immunological non responders. We were people who had suppressed our virus with the available drugs. But our T cells never rose like a lot of people see cells rise when they get on effective treatment. But most of us started late or for whatever reason, we didn't have that rise in T cells. So we entered the study as a result of this one infusion of these manipulated cells. We all had a doubling of our T cells. It's been nine years now. My T cells have remained at that level. Remember, I'm still on treatment, antiviral treatment, but I shouldn't have gotten a double t cells just because I was in this trial. Is everybody get that? Explain that.

[00:34:03] Good enough? So that was. Thank you.

[00:34:07] I think that's a great example of why, you know, Matt described is called a first a human trial. And you don't know what's going to happen. The doctors don't know. The patients don't know. We had results in mice that, you know, where we gave HIV to mice. And it looked promising there. But what we saw in humans was not expected. I mean, I had one patient whose CD4 count went to twelve hundred and was above normal. So all sudden he's above normal. And it all he'd had been in the basement before. And so, I mean, the patients really I think have benefited from that bit. And that's not what we are looking for. But it happened and it was reproducible. And so now, you know, there's a lot of new doors to look at because of that unexpected finding.

[00:34:53] Can I just say add one thing. When they presented the data for this study, I happened to be in the audience. I think it was here. It may have been it may have been in Boston or here. I was sitting in the audience and they showed the they were presenting the data. And I knew my number, my patient number, and I saw it on the graph. And literally, when they showed the T cells slide with everybody's T cells doubling the audience, scientists gasped. You'd never hear that. You rarely hear that at conferences, but you could hear an audible gasp. This had never been seen in gene editing study before. It was quite, quite an amazing time. And for me, I was like, there's my number. It's good. It's going up. It was great.

[00:35:37] It was great.

[00:35:40] Thanks. That's a loaded question, too. So when protease inhibitors came out for me, I kind of got this, oh shit, I'm going to have to get a career moment and decided that I need to go back to school to get it. I'd already been doing like harm reduction work and stuff and I decided to go back to school so I could get paid like the other people that were doing that job. And I stepped away from activism and just kind of followed it. But my experience on antiretroviral treatment is is one where I frequently became resistant to drugs. Up until the drug Isentress came out, I would usually have around 300 t cells as a baseline and I would have a 20000 copy viral load as a baseline. And for some reason by the time like Matt, but not as drastic or dramatic. By the time that Timothy Brown was cured, if I can use that word, I was left to just two protease inhibitors and an entry inhibitor called Isentress. And that was the first drug that got my viral load down to zero. I kind of known about the CCR-5 for a long time since the early 90s. And what piqued my interest was when Timothy Brown was cured. And I started to really think about like, well, you know, someone's been cured. Like you make this research happen, you know, like maybe this you can replicate this in different ways. And what I'm trying to say is that I got this kind of tinge of optimism and hope that I just kind of been gliding along like like, okay, I'm on meds and working and stuff and activism changed.

[00:37:26] I don't really need to do that as much. And so I've always been in touch with Matt. We go back way back. Like I said, and I knew about his study and when it when that happened. And I pay very close attention to it. I'm also somebody who's like. Like, I go down a rabbit hole with research. Like, I just have to understand it. And until I know it's all just bat my eyes and ask somebody to explain it to me until I got it. So when his study came out, I could see the changes like I know him without him telling me. I could see the changes when the study I was in is what's called a Phase 1 2 study. And what they were doing is when you get your altered cells, you have to give something to suppress the immune system. So what they were trying to do was to give a dose chemotherapy and they were trying to what they were doing is called dose escalating to see like how much can we give that people can tolerate that affect your immune system enough so that you'll accept these cells in the transplant, for example, all the time. You know, people often don't get the kind of suppression that they need. So it's a well-known thing. And so I think I was probably the sixth person that got cells. I had already been through chemotherapy before I had had lymphoma, stage three lymphoma. So I gave what's called a CHOP with Rituxan.

[00:38:52] And so what I'm trying to say is that the chemotherapy they gave me was nothing compared to that. So, hey. Yeah, no problem. I feel kind of crappy for a day. And so I tolerated really well. I might have been in a bit of an anomaly because I had six bags that they grew out. And when they grow out your cells, they put it in liquid nitrogen. And I had a bag that broke. But so what I'm saying is it took me about an hour to get my cells. So I didn't know back then that that was a large number of cells. Now, I don't know if that had anything to do with why I'm in the situation I am in right now. I should really say, though, like I went into the study not thinking that I'm going to be cured like Timothy Brown. That wasn't my motivation. My motivation was that if you're going to cure HIV, genetics is perhaps one of the ways to do it because it's already been done. And maybe that's the. Maybe that's the answer. And I'm willing to participate in something like that. I think it's a it's a very important question to answer, even if it's even if it fails or even if it just gives you more information to go on for perhaps combination therapies of other kinds. It was planned that I would go off meds. You stay on your meds for 12 weeks. And then when I stop meds, it was it was really interesting. I mean, I think going back to something I said earlier today, like for me when I was taking HIV meds, I I just daily reminder of this whole disease of society.

[00:40:21] I know I keep saying that. But it's actually true that I take my meds and I would think about it like like, oh, yeah, you're taking all your dead friends and all that kind of stuff. And it was just something that really stuck to my mind. So that's, you know, like all the sudden you're not like, oh, you know, I'm just not doing this. I didn't physical feel a lot different, to be honest about it, but it's interesting to just roll through that experience. I, again, I tolerated the treatment really well and very fortunate. And my kind of thing now is that I know I still have virus and sometimes I think it's not a if it's a when like someday this might take off and I'll get back on meds and I'll just write it out as long as I can. Actually went through chemotherapy and

radiation again in 2016 while I was in the study and much to my doctors' dismay I did not go back on meds. I was like let's wait and see on some labs. And what happened is, is that ever since that point, my viral load was actually lower than it was before. And they think it's maybe because of the radiation. But it stayed at 100 or below. T cell rebound is kind of the same kind of bounce between 300 and 400. I didn't have a big huge increase in T cells except for right away, which were 24000.

[00:41:44] That was my first T cell count was twenty four thousand.

[00:41:48] So I'll ask one of the last questions for the panelists. Then I will open it up to the community here. So my question would be for Dr. June, what is one of the surprising findings that you see in the field of cell and gene therapy? And then I want to refer to the documents that are at the table in the back. So as that was alluded to at the beginning of the meeting today, is that the defeat HIV Community Advisory Board has conducted social science research on topics of cell and gene therapy or other cure approaches to HIV. And I want to ask a question from one of the focus groups on acceptability of cell and gene therapy. So on top of the surprising findings of the field of cell and gene therapy, one of the questions that was raised in the focus groups was how are adverse effects taken care of in these kinds of trials?

[00:42:40] So Manuel, the first thing is, I mean, the biggest surprise to me now is that cell and gene therapy has become accepted as I mean, it's a new pillar in medical care. So it will cure diseases that were previously incurable so that in 2017, the first gene therapies were approved for leukemia. Very soon, you know, an incurable disease is sickle cell anemia. That's going to be curable with gene modified stem cells. It's a huge breakthrough. And this science is amazing what's happening. But I want to caution you, it's going to take time to this goes out. I think it's 10 years really for HIV to we have something that's FDA approved. It goes faster in cancer, you know, because you can take more risks there. But what cancer has done is pave the way for a non-fatal disease like HIV. So I am confident it's going to happen because we have the scientific tools, you know, from gene editing and others may making new kinds of cells and so on. So it's really a very amazing time now. It's a question of how long it will take. Now, the side effects, you know, we don't know. Everyone's followed right now. If you get a gene modified cell like the two Matts did, you're supposed to be followed for 15 years. And the FDA is doing that. It's a very good policy. So we know if there's long term effects. And I mentioned, you know, the first patients we treat with CAR T cells with HIV in 1996, we treated 40 of them. A lot of men, San Francisco and some in at Harvard. None of them have had side effects and they've all been followed and they still have the CAR T cells. So we think it's very safe. But, you know, each of these things needs to be tested. And unfortunately, and in a disease that's not cancer - it takes longer. You have to be very careful. So we need to be, you know, aware it's going to take longer than we wish it would. But I am really confident is going to happen and this next decade.

[00:44:44] Audience time. So anyone have any questions?

[00:44:49] I just really want to make a comment more than a question. I want to thank your you for your activism in Act Up that it's your shoulders that those of us living with AIDS stand on. And we owe you such a deep gratitude. Gratitude. Thank you.

[00:45:16] What was it like to go off therapy? You know, if you increase you now and all the emphasis on untransmittable, undetectable, what was it like to go off therapy and not be on pills? You talked about the upside of not being reminded, but was there a concern about that? And like you say, your viral load may rebound at any time. So you don't know when that might happen.

[00:45:36] I knew I was going to get asked that question and I knew I wouldn't have a good answer for it.

[00:45:42] So I think part of what I hear in that question is, is do I have some level of fear about whether my virus is going to take off or something?

[00:45:53] I actually am pretty confident that there's so many different classes of drugs that come out that I really don't have that fear. And the other part about that is I accept I'm going to accept whatever comes my way. It was because, in other words, like, why shouldn't something bad happen, you know? You know, things like things like that happen in life all the time. You know, why would I be an exception to it? But it is interesting. Again, the psychology of not taking medications, is this actually really, really interesting. I had been. It's a routine. It's part of life. It's it's part of who I was and who I am, I should say. And I never really had an adherence problem. In other words, you know, I am not perfect. I don't know anyone who is with adherence. You know, I'm sure there's people out there that were that are. But like, you get up in the morning and take your meds, you know, you take, you know, in the middle of the day and then you take them later. And it was just became routine. So that routine changed. But I'm also on other meds. I still take those, you know, they're not HIV meds. But, you know, there's there's other things like I'll spare you that. But. So I hope that answered your question. I don't have a big robust answer to that question, though. I think another way is everyone would probably have a slightly different experience.

[00:47:20] What about opportunistic infections like Kaposi's sarcoma and the disruption associated with antiretrovirals?

[00:47:29] I think Dr. Jerome here knows more about that than any of us up here. You know, Kaposi's sarcoma is caused by a herpes virus. And so there are therapies directly aimed at that and there are therapies directly aimed at improving your immune system so that it can control. So I think just like I mean, you heard Matt here say he got lymphoma and there are HIV associated lymphomas and there are specific therapies. But one of the best things is restoring the immune system. And then the you know, the chance of getting secondary cancers like opportunistic infections goes down.

[00:48:08] So one of the drugs they take is a gram of Valacylovir, which I was on anyways, because I have other viruses like herpes and don't like to say that publicly. I don't know why, but so that might be one way that it's addressed. I don't know. I actually never got KS even before the before antiretrovirus came out. But one of my best friends died of it. He got it in his lungs and he went really fast.

[00:48:37] Jeff, I think one of the things I think about is, I mean, this is really a whole new era.

[00:48:43] I mean, if we get to this point where we can get people walking around like Matt who can be what we call the term is functionally cured. Right. So you still have HIV in your body, but you're probably going to be so low that you're not going to be able to transmit. But the point is that if you get to that point, you're hopefully going to be followed. So you can continue to monitor yourself. Hopefully, it's a it's a whole new area of discussion. I think we need it. We need to talk about as a community, if we ever get to that point where there is a lot of people running around with, you know, that are as lucky as Matt is right now. And the other thing I was going to say is that we you know, we're faced as we get older with HIV, with a lot of these diseases that people that grow old with get are getting or getting them earlier. And so what's the tradeoff? I mean, we're going to we're going to be dealing with some illness at some point in our life. Might as well X out the HIV part and move on with whatever we're dealt with.

[00:49:52] Yeah. My question is, with even low levels of virus production, is anybody been looking at what the effect would be on the inflammation? Because we know the inflammatory process is significant. But have you studied, say, before and then after? And to see how the inflammatory markers may change?

[00:50:16] Well, I mean, that's a great question. That is right. I mean, today we had our Advisory Board here for this and one of their central research missions is to study low level inflammation. And can you develop a way to treat that? So it's there is a fundamental trial done about two years ago that had a very surprising result. So one way you can stop chronic inflammation is by blocking a cytokine called IL-1 Alpha and Novartis made a drug that does that. And they gave it to see what it would do in people who were at risk for heart attacks. They'd already had a couple and they found out that it cut the risk of heart attacks in half. So by blocking inflammation, it did that and ran much. And also the incidence of new lung cancer went down by one third. And so it's thought now inflammation leads to cancer and it leads to the problems in HIV, you know, with the accelerated aging and so on. So if we had general ways to do that that are safe and I am sure they're going to be tested in HIV. So the issue in HIV now is, is can you imagine suppressing or would you lose control of the virus? But clearly, we don't know why people, even with very low or undetectable copies of virus, continue to have ongoing inflammation, CMV and the clearly as one of them. So that's another virus that most of us have.

[00:51:48] I was just going to ask Carl, isn't it? Everybody reaches a homeostasis in their immune system, which has to do a balance, which has to do with inflammation partly. Right. So everybody has a different kind of place where they would I would, as I would wonder, get sort of inflammatory disease.

[00:52:09] Yeah. So, you know, a. And that's exactly right. We all have set points. About 20 percent of people have an overactive immune system and have auto immune diseases like psoriasis, like lupus and arthritis.

[00:52:23] So that's about one out of five people, you know, have a hyperactive immune system and that can lead then diseases like arthritis to diabetes and so on. And other people then have immune systems that are tuned down and they may actually get more cancer because the immune system can be out on the hunt for cancers. And, you know, and we have, as you know, you know, people with HIV, the elite controllers, maybe one in five hundred thousand people get HIV. They don't even need drugs. Their immune system can handle it. So we have a huge spectrum within humans because we're not inbred mice of how well the immune system works. And so one whole field of immunology research is aimed at making it better. So that would help control HIV and some kinds of hepatitis. And the other is to turn it down so that we could control autoimmune disease as well.

[00:53:20] That's a brilliant question. And then just as a practical thing, my experience with my own primary doctor is that he's not going to look for a lot of things unless I have something going on like a D-dimer, for example. So I think it's also a matter of if it's standard of care to

even look. What would be inflammatory markers? Because it's just not like my labs are just like anyone else's. I get what's called a CD4 panel and some viral load information. It's not going to like go search out other things which I don't even know and can't tell you, you know. But I think that that is part of it is is what standard of care is. The standard of care. Have that philosophy to look for it even.

[00:54:01] Great question.

[00:54:03] Dr. June, do you think it would be good to look at the purinergic system since it's intrinsically linked to the inflammatory process?

[00:54:15] I mean, that's a deep scientific question. There are inhibitors being tested and, you know, we don't know yet. I mean, I think different. I mean, what we know is an inflammation is that is central to a diverse disease like atherosclerosis, which everyone thought was all cholesterol. That's actually a lot of inflammation. How you. What happens when you get HIV, even things like Alzheimer's. Now, inflammation looks like it's part of dementia. So. So that's what inflammation is. But what causes it in different people can be different. So some people may be purinergic based in others, it might be IL-1 Alpha. That's where I think the heart of personalized medicine is. It's going to be dissecting your immune system and then finding, you know, the right, you know, therapy for your particular immune system.

[00:55:08] Just quick question, Dr. June. You mentioned that there was a 15 year follow up by the FDA. Can you tell us a little bit about what happens during those 15 years follow up? Sure.

[00:55:17] Basically, you know, the patients get mailed a postcard that says, are you OK? You know, and if you had any, you know, untoward things happen and one tube of blood is frozen down every year and then if something happens. So the whole reason that if someone gets an unexplained say, for instance, some kind of cancer, that's rare, you can look and see maybe did this cell or gene therapy contribute to that. So it's a very forward looking thing. You know, we know in cancer chemotherapy that, you know, chemotherapy causes. If you look at the people cured like women with breast and ovarian cancer. About one in 10 will get leukemia later. So the chemotherapy actually can cause leukemia. And we never had that kind of database looking to see who would be at risk for that and so on. So this is a really forward looking thing. They don't do it in China.

[00:56:11] I can tell you that like we do here.

[00:56:15] Thank you for your inspiring story. I guess my question is to Dr. June. As far as I understand it, the HIV is integrates into the genome, and that's part of why it mutates so quickly, is that it's a lossy process. What is there? As far as it's in the gene editing community, there's a there's a hesitance to using a viral transfer mechanisms. Do you think there'd be any a will to look into using the HIV capsid to deliver maybe a CRISPR system for integrates? Yeah.

[00:56:47] So there was just a paper about, you know, can you find a magic scissors that would go in? Because HIV goes into your T cell and it goes, you know, you have 23 chromosomes and it goes into any one of the twenty three. And so finding that it's not in the same place in every cell. So you have to have something that would find that needle in the haystack and CRISPR can be it can be done that way it looks like now. So the question then becomes, you know, if it could be excised out, would it be efficient enough to give you a cure? And so, I mean, that wasn't. People would have laughed if you would have said that five years ago. But that technology has gotten so much better that now it's on the table. So it's optimistic that that can happen.

[00:57:35] You know, and that with other cell therapy approaches, I'd like to ask a more general question. We're talking about some pretty sophisticated approaches. I'm wondering about what is the availability of health care to HIV affected people and in their access to any or all of this stuff.

[00:58:04] You know, that's a huge, you know, worldwide that's a huge issue. Most people aren't treated and most aren't suppressed. And so my, um, what I'm talking about is at the leading edge of a bubble. And then hopefully this will come out so that it will extend later on. I mean, but we have, as you know, huge health care issues even in our own country, which is are just hard to understand. But let alone when you go to other, you know, a second or third world countries. So what we're talking about now is what could be done. And then, you know, then the whole other issue is this how would you move it out into the community?

[00:58:43] And then to follow up with that question and the handouts from the back, there was that map on the bottom that shows the distribution problem. So like the little circles are the countries where that the technology is available. And as you can see, there's only like seven dots across the country or across the world, seven dots where this technology is available. So yeah, that that really does speak to kind of the limitations right now. But as Dr. June was saying, and then also in that map of the current and future landscape for HIV, it's going to take

a long time to build the infrastructure going forward and maybe a decade, maybe 15 years. It's a challenge. Some of those like systemic problems in the first place.

[00:59:30] So a couple of years ago at this meeting at the cell and gene Therapy HIV Cell and gene therapy conference, a woman presented a an instrument called gene therapy in a box. I don't know where that is now, but it's at.

[00:59:45] It was actually a way to to sort of put all of the instruments and the tests involved in doing a gene therapy study, you know? What have I tried to say in smaller system so that they didn't have to go to the clinic after clinic after clinic, but they could do it.

[01:00:04] I could do this setting in a basically is it a mechanized box that they could take to a clinic in somewhere in Africa? And so I don't know where they are with that, but that's a step forward and that's for gene therapy. But you're talking about just basic health care needs, which is always going to be a problem, I'm afraid.

[01:00:23] It just reflects what America is. With all of its racism, with all of its fascism and all of its disparity with income, I think that it's a great question. And I think that the reality is there's disparate care around. I mean, I think that's no no surprise to anybody. Unfortunately.

[01:00:43] I mean, as an example, you know, the number one cause of death now in the United States is cancer. When I was in medical school, it was heart disease. In Africa the number one cause, you know, is infection. And only now is cancer becoming an epidemic because people didn't live long enough to get it. So we have this huge issue of health care disparities and and the diseases that happen and change depending on how good the health care is. I mean, now in the U.S., as cancer starts to get cured and there's a lot of hope on, it's gonna become Alzheimer's and dementia becomes the number one problem.

[01:01:20] So in some of the the work we've done in the Community Advisory Board, talking with folks with HIV and their concerns around cell and gene therapy, some of the things that come up are peoples, you know, questions around, procedures and questions around, you know, what are the things I might need to worry about? Am I going to lose my hair? Am I going to throw up, or am I going to grow a sixth finger or breast, or am I going to get cancer? And what kind of monitoring is there? Am I going to need a spinal tap? You, Matt, you spoke to your experiences. And so, Carl, kind of based on on where the therapy is now and what we know, what do you think are the things people maybe should be concerned about versus not

be concerned about with this kind of therapy? And what kind of monitoring do you think people should have?

[01:02:15] You know, that becomes very much depends on the details of the trial. So some of these trials are very, you know, like the ones with, you know, like the Tim Brown. So for people who have a cancer and go through a bone marrow transplant, I mean, they're going to be very sick for sure. They're going to be in a hospital.

[01:02:36] And that's very different than some other observational studies where you might change medicines and see if you can get, you know, the dose of it improved. And it's an outpatient. You know, where there the biggest problem is people can't get to work. And how much time is it going to be away from work? Can they afford that, too? So so there's this huge spectrum. And I think, you know, the physicians have to have and the patients have to have trust in each other so that all those questions can be answered ahead of time.

[01:03:08] So in the CCR-5 gene, it sounded like you said the Europeans have it because of the plague. So for non-Europeans, that is the result, just as effective.

[01:03:22] Oh, yes. So, you know, with the gene therapy, the gene that goes in is exactly the same as what you would have inherited. So it works that way. Now, there was, you know, got a lot of bad press last year, in China. You know, there was this case with a dishonest scientist. It so called the CRISPR babies and tried to make Chinese babies resistant to HIV. You know, before they'd even been born. And so that kind of has given a bad name to that. But I mean, you know, so. So he was doing that to Chinese. It works. But the problem is that that was an unethical experiment.

[01:04:00] So my question is for the two Matts. When you all were diagnosed as HIV positive way back in the day and you had friends who also were. Did any of your friends get fed up with all the red tape and say, like f this and go elsewhere for treatment like outside of the U.S. and what were their outcome? Boy, it takes me back.

[01:04:21] But yeah, there is a whole, you know, back. Yeah. Before we even had any antiretrovirals, we you. You see the Dallas Buyers Club. There are Buyers Club. So we ran one in San Francisco called the Healing Alternatives Foundation that I ended up being a director of after several years of of no therapy and as probably about five or six years of people desperate for treatment, there was nothing available. There was no go to Walgreens to pick up your pharmacy, your drugs. So what we did is there were people who actually were runners,

went to Mexico, Japan, places where there were alternative quote, alternative complementary treatments, but bring them back into the country they ended.

[01:05:07] And Matt mentioned bathtub ddC. People were actually copying the that I have to tell the story because it's I think is an amazing story. A guy was a guy that went to a medical conference and they showed the first study of ddC. And often at these conferences, they'll show the chemical structure. He took a picture of that and used that picture to go back to his lab. He was a chemist, so he could actually go back to his laboratory and recreate he recreated it. Now, mass producing that, you know, scaling it up to production where each pill had the same amount of drug in it.

[01:05:46] There's a whole lot of different levels of of faults in doing something like that, which is what happened. But we you know, we did anything we could do. People were desperate. You know, oxygen therapy, heat therapy, anything you could do. Remember Matt? I mean, it was like AL-721, the egg lipids. So you did what you did to survive. And, you know, for whatever reason, some people got through that or are still alive today. Others, you know, mostly they're not. In desperate times.

[01:06:21] People do a lot of desperate things. And if someone hangs onto something that someone like, let's say, oh, you take 500 vitamins a day or something and they do it.

[01:06:32] The one thing that we always did in forums like this is not really have an opinion about like, hey, do that or don't do that. That's up to the individual. But at least you have the proper, you know, how informed are you about what you're doing? I used to do a hotline, which was just like an HIV 101 hotline for Project Inform. And I did it on Saturdays and we had the cure of the week where we get calls with the cure all, come down and heat up your blood. And it's good to like it's called hypothermia. Like like we're going to get rid of your HIV that way or here do some ozone. You know, it's all of stuff, you know? Oh, and there was this thing called DNCB, where it's a photochemical and you put it on your skin and you get what's called a hypersensitivity reaction. And it's like you can see it. So it looks like it's doing something. It's not going to hurt you. But there's a lot of belief behind things. And as you know, with beliefs, beliefs are hard to change, even if you have fact.

[01:07:31] Hi there. First and foremost, thank you for all the work and the contributions that you have done throughout your career and throughout your lifetimes. So a couple of us in the back. We actually are representatives of the vaccine trials, you know, as part of Fred Hutch. So we're on the outreach team and our job is to run out into community and actually recruit into a lot of up and coming clinical research studies that are happening right now by the Hutch. And it's

really cool and inspiring work. But some days it could be really hard. It's hard to talk to a complete stranger and have them try and find some kind of connection to HIV. A lot of times you get questions like, so what? Why does HIV affect me? How can it affect me? I am in no way related to this issue throughout your lifetimes and experiences. How do you answer that question in a way that feels authentic to you? Cause sometimes it's kind of hard to answer that in the moment.

[01:08:27] I mean, I think part of it is the kind of world we live in where people are distracted by their cell phone constantly. And, you know, it's very easy to live in a silo even though we have all this mass communication. And I think one of the things one of the ways that I would approach it is to really talk about that is something that might help somebody. You might actually save somebody's life. And but also be realistic that it might be something, you know, they're not treatment they are trials. And and so one of the reasons to participate into the trial is like, hey, I want to volunteer to see if something is going to be a really beneficial answer or not to a question. And I think vaccines have a lot of history with a lot of that isn't good. Or they may not get a benefit at all because it's a really complex thing that I'm sure the researchers could elaborate on. What I really like is I checked out your information about it and it rocks like this. Really? It's really like. Like, hey, this is what we're doing. It's really simply put, it's really matter of fact, it's really digestible. And like even I can understand it, which is great. You know? So I was looking at your stuff and that kind of thing. And that one to one communication like it, it might not affect somebody like in the moment, but five years down the road, it might. You plant a seed in someone's you know, you lease your plant a question, you know, something that might have a humanitarian benefit. You have a hard job.

[01:09:57] Yeah. Let's give them a round of applause.

[01:09:59] I mean.

[01:10:03] I mean, I did outreach for treatment trials for the AIDS clinical trial group at San Francisco General Hospital back in the day, and I was hired to go figure. They wanted me to enroll and reach out to women and minorities didn't work very well. But what I did learn was if I got it inside of an organization and I was able to do a presentation and sit people down and have a meal, talk about the science a little bit, get people a little bit thinking in their minds about what what you're talking about.

[01:10:43] This was treatment, not vaccines are a lot harder. It's a lot bigger road, so to speak, than treatment. But back then, if I if I could just have a moment of their time and got a little bit

of their trust, then often it was helpful. But as soon as, you know, I was the wrong hire for that job.

[01:11:05] The co-panelists. You all want to take a answer for that question. I feel like all of us are in different spaces and we all more or less get confronted with that question on a regular basis. The question was along the lines of like going up to a random person and trying to explain what we do in the field of HIV. Why does it matter to me? I don't feel like I'm a risk. Okay.

[01:11:30] Well, for me, I know that there's not a very big language where black and brown men that look like me and my community. So just two months ago, I went inside of a church and talked about my status and let them know that this is this is where I'm at. 1, 1 and 2 black men will be diagnosed the next the next following week. We had an 80 year old lady that went to my church coming to get tested. I think that HIV saved my life. So at this point, I'm fearless. As long as I'm getting the message out and speaking about it openly, they will. If you build it, they will come. It's how I look at it. So. Actually, that was going to be my next question. When I look and, I and I see the trials and the vaccine trials that go on, I think about Philadelphia, I think about Atlanta and I think about D.C., where primarily one or two black men would be diagnosed with HIV. Have you guys heard about any trials that are going on in that area? Or or how do I get the language when it comes to the vaccine trials within my community?

[01:12:37] There was a vaccine vaccine trial network that gets out the information. There are the trials that are available in Seattle and in San Francisco, L.A. are usually available in other major cities. The fault comes in rural areas where the trials, rural areas are very, very difficult places to have trials because obviously there's not enough people to run them. But I think I think what you're saying is there still inadequate trials for people of color and women. And I think there's a lot more work being done in inclusion in making those trials happen. But if there is one, resources are very valuable for people to look up. And that's the clinical trials dot gov. Thank you. Clinical trials dot gov G O V.

[01:13:25] There is a great search engine type in what you're looking for and look into your city and see if the trials are available there. You should. People of color and women should not be excluded from from clinical trials, but they often still are. I mean, they are still excluded.

[01:13:45] Yeah.

[01:13:45] And we have very carefully tracked that to make sure that we have representative, you know, on enrollment in our trials and what we're actually doing pretty well on that. But it is an issue, you know, as it's been said, you know, because if you don't. So you need to have full employment to be on these trials a lot of times. And so if people are homeless and so on, it's a lot harder to get on these trials. And so there are socio economic issues that need to be dealt with.

[01:14:17] That's a great question. I think, too. I mean, I think what's beautiful about this forum is that it brings people together. And I don't know my experience. I didn't say I work at a hospital. I'm a social worker. I'm one of those people who goes and talks to your bedside. And I tell someone, hey, go to this website. I don't know if that's really connecting with them. I mean, you know, it's it's maybe they will. Maybe they won't. But I think I love what you did at church. And in other words, you got to go there. You got to be there, you know, like like and make it make a connection. You know, it's it's like for me, like half the time someone tells me to go to a website, I'm like yeah, alright, whatever, you know.

[01:14:58] And for the HPV vaccine, we went out to the local churches and that's how we got the message out so that everyone would get vaccinated.

[01:15:07] Thanks, Stephaun Wallace. I'm actually responsible for community engagement and social behavioral science and the HIV Vaccine Trials Network globally. So I wanted to add that we do have HIV clinical trials going on in different places and certainly education is happening through our clinical research sites. But I wanted to sort of put into this space that, you know, one of the things that we also see is that there's a lot of consideration and not just sort of communicating education messages about vaccines, but also not appearing to to unduly influence participants in clinical research and particularly thinking about the complicated history that black communities have regarding research. And so what does it mean to to work, to advocate and to educate communities, but also not look like we're targeting them in a way that that communities have also been targeted in the past. And so it's a it's a balance and certainly work with. Again, our sites like the Seattle site here, as well as community based organizations locally and nationally and globally to help spread the messages. But there's still lots of work to do.

[01:16:19] As a person who's had HIV since the early 80s and I'm had a very successful ddC, not my favorite, by the way, my toes are still telling me that.

[01:16:32] But I've had very consistent success over the last few years. Undetectable. Pretty good sized T cells. At what, there's two questions, really. At what point do you decide? Gosh, I

think I'm in a cash in my chips and take a chance or I don't want to be in a position where I'm desperate either. And it's not I'm not articulating a question. Well, but I think when you're having treatments that are working, deciding when things are working to take a risk is a big question. And I did remember my second follow up question. So if you decide you you want to do something for whatever, the driving reason is how do you know which one of the variety of things. Because there, you know, you've been talking about CAR. You've been talking about many things. How does someone how do you know? I mean, I know it's it's I've been in a couple of trials for other things, and they didn't really go anywhere. But I have a pretty solid quality of life.

[01:17:41] And I don't know that I want to put that at risk even at the benefit of the mass, which I've been thinking about this is we've been sitting here and I'm just about to retire from a long career. And I think, gosh, would it be worth it? I think there might be this opportunity to give back in this area, but it would take a risk. That's where it all comes down to the word at the end, the risk.

[01:18:11] And that's. You just answered your own question. It's really about risk versus benefit. And it's hard to determine that when you're doing well. And that's the big conundrum right now in Cure Research is how are we going to recruit and enroll people in these studies when people are feeling well? And my my answer to that sort of a response is to look at other disease states where people are doing well. How did they recruit studies for those disease states? It's still not going to answer your full question, but it might help in determining where to reach out to people and how to get people enrolling in trials. I think the big thing is it's a personal decision. It's still going to be a personal choice, informed choice. And that's the other problem is how much information do we really have about these particular new, you know, modalities that we're using? So, Carl, do you want to add anything?

[01:19:16] I mean, I think you've hit the nail on the head. So part of it is the altruism part. And that depends on each person's own individual setting. And then, I mean, you know, the Matts here had their backs against the wall and weren't in your setting. And so so that's another motivation. And so their risk benefit thing would be different from yours. And so, yeah, I mean, you need to look for trials and do your due diligence, you know? What is the best estimate? You know, if you're the first one on the trial, the risk is higher than if you're the 30th person. So I think, you know, you. I think it's a great question you're asking and your answer is gonna be different from other peoples, and that's how it should be.

[01:20:00] One other thing is to look to see how many invasive tests are requires in the trial, like spinal taps, things like that. You know, you want to assess all that. Are you willing to deal

with that or not? Do you think your outcome is going to be improved because of it or not? Maybe it won't, but maybe for the good of society, we'll find out something.

[01:20:18] So it's really a tough question.

[01:20:22] I think it's a great question, too, because I think it really hits some of the nail on the head about like, hey, you know, you know, my viral loads undetectable. I've been on treatment for years and it's like I'm not having any problems with medications and my life's good and I'm working.

[01:20:41] And then so what would be my motivation? You know, I think it comes down to that. Like for me, like my motivation for being in this study was like, that is a really interesting question. If I can participate and help lead to some kind of answer from that question, that's that's all I'm doing. That's my motivation. I mean, I think it goes back to like I can't stress morally trials are not treatment. They're not you know, they're trials. You're a guinea pig. It's true. You know, and I think one thing about community based advisory boards, it's great, is you get to do you the. Get to look at the informed consent in a really good example of a really tough informed consent was the IL-2 studies because it has a million side effects and they suck, you know. So it's I think it's it's really comes down to like motivation. That's that's my two cents.

[01:21:38] All right, let's.

[01:21:40] Thank you. I want to thank you all for coming tonight and asking these great questions. Before we let them go, I just wanted to sort of give them some things. And so we have a defeat HIV tee-shirt for each of you there. And so we have these pendants from Mexico City here. Take one down. Pass it around. All right. Thank you all. Be sure to get home safely. And blessings to everyone. Chao.

[01:22:09] This podcast was presented by the Seattle Public Library and Foundation and made possible by your contributions to the Seattle Public Library Foundation. Thanks for listening.