

## THE BLOODLINE WITH LLS

A PODCAST FOR PATIENTS AND CAREGIVERS

### ***Episode: 'Understanding Racial and Ethnic Disparities Within Healthcare'***

#### **Description:**

Join this insightful conversation as Alicia, Edith and Lizette sit down to chat with Dr. Stephen B. Thomas, one of the nation's leading scholars in the effort to eliminate racial and ethnic health disparities. Dr. Thomas is a Professor of Health Policy & Management and Director of the Maryland Center for Health Equity at the University of Maryland School of Public Health. On this episode, Dr. Thomas explains structural determinants of health and defines 'health disparity' and 'health equity' as it relates to ethnicity and race in America. Dr. Thomas emphasizes that only together can we create lasting change and better outcomes for *all* people. He explains how his students and colleagues continue to think outside the box when creating ways to bring education and awareness to those within marginalized groups. Dr. Thomas shares the results of various research studies, current trends and future projects that help to address racial and ethnic disparities within healthcare.

#### **Transcript:**

**Alicia:** Welcome to *The Bloodline with LLS*. I'm Alicia.

**Edith:** I'm Edith.

**Lizette:** And I'm Lizette. Thank you so much for joining us on this episode.

**Alicia:** Today we will be speaking with one of the nation's leading scholars in the effort to eliminate racial and ethnic health disparities, Dr. Stephen B. Thomas, Professor of Health Policy & Management and Director of the Maryland Center for Health Equity at the University of Maryland School of Public Health. Welcome Dr. Thomas.

**Stephen B. Thomas, PhD:** What an honor to be with you today.

**Alicia:** We are very excited to have you. Now before we start, should we call you Dr. Thomas, Dr. T., Stephen? What do you prefer?

**Dr. Thomas:** Well, as we get into it, my friends call me Dr. T.; and your organization is definitely a friend.

**Alicia:** Awesome. All right, Dr. T. it is. So, before we begin our conversation about today's topic, "The History of Health Disparities," our listeners like to hear a little about the speaker's background. So, to give a little more information about yourself, Dr. T., what led you to your profession and field of interest overall?

**Dr. Thomas:** Well, I worked my way through college working in the hospital. My mother was a nurse. And I grew up in Columbus, Ohio, and there were six of us, three girls and three boys. But I'll never forget that my mother as a nurse now in her white uniform and white shoes back in the day when nurses looked like nurses, I was always intrigued by that, and so I, was one of the first wave of cohorts of people trained as respiratory therapists.

When many people were coming into the hospital suffering from chronic obstructive lung disease. So I had a front row seat of dealing with a chronic disease in a crisis mode, being there when they did Code Blues to revive someone, being there when we would have to put an intubation tube in and, unfortunately, watching far too many people die.

My interest was to pursue medical training; and at some point, I realized and said to myself, do I want to spend my entire career at the end of the line? You know, when people are coming in, yes, we can do marvelous things, miraculous things; but their lives were cut so short, and the quality of their life so diminished.

I had never even really heard of public health, didn't even know what it was. And in 1976 I had an opportunity to take an international trip. It was the first time I've ever been outside the United States, and it was to the Peoples Republic of China. There were 20 people on the trip. I was the only person of color. I was the only black person on the trip. And when we got to Beijing, the Chinese actually pointed it out. They said, "They must have sent you to lead."

But, and the reason that, why that was so interesting is because in China, the revolution was the working man was now on top. They call it bottom rail on top. So “They must have sent you to lead,” is what they said, and it always stuck with me.

The other thing that stuck with me, I came down for breakfast one morning, and there was a table of about eight or nine black men and, and one white man. And I was so amazed, given I was the only black person on the trip. I went over to that table, and I said, “Hey, what’s up?” And they looked at me like I was from outer space. They only spoke French.

They were from a French-speaking country in Africa; and they had a white physician that was with them. And they were there in China to be trained, ready for this, as barefoot doctors. And I was so intrigued by this model in China of bringing healthcare to people in rural areas, of training lay people, local opinion leaders, and giving them some medical training so that they could provide care in rural areas.

And so that idea has stuck with me to this very day. In discovering public health, I finished my undergrad degree at The Ohio State University and then went on and really never stopped through my master’s and then PhD, all in public health, community health.

And my entire career has been focused on how to translate the evidence of science and the science of medicine, the science of public health, how to translate that into culturally tailored, community-based interventions. And today what that looks like in my world is, believe it or not, mobilizing black barbershops and beauty salons and transforming them into health information portals.

And that’s because these are places in the African American community where people literally have a tremendous amount of trust. They’re all mom and pop operations, and they’ve been with us since the 1800s. During the time of slavery, they had been with us.

And so to raise to barbers' awareness and the history that they play in America, to recognize the role that they play as a trusted venue, and to recognize and tell my health professionals, colleagues that we need everybody at the table. They may not have degrees like we have, but they have trust and credibility; and I think that's what we've lost in our professional education and training. We come out as professionals, but, somewhere along the line, we lose some of our humanity. And I think we have to get that back. It's time to recommit ourselves to some of the core values.

It's COVID-19 that now has really raised awareness of the entire American people to what public health is. And many of them have never heard of what an epidemiologist is before, let alone social determinants of health or even the word health disparities. But now that is out of the margins of academia and now in mainstream conversations.

And that's why I'm so excited to talk to your audience about health disparities and how we can, in this space of health, in the midst of a global pandemic, that we may well be able to bring our country back together through some of the core values.

**Alicia:** You mentioned something earlier that I said stood out to me when you were made aware of your own limitations when you traveled to China, right, and you saw the different people; And I think that speaks to the beauty of exploring and learning, and what it allows us to appreciate, you know, so much more of this world once those two things are done..

Today's conversation with you will be about the history of health disparities. Now in order for our listeners to follow the conversation, I think it's important to define the terms that we'll be using. Health disparities and health equity, would you mind defining those two terms for our listeners?

**Dr. Thomas:** I think it's very, very important because now they're hearing those terms in popular media; and nobody's really defining them.



Now, you know, while some differences in definitions may reflect, you know, stylistic preferences, as well as health, inequality or health inequity, I mean all these little subtleties. The key is that words convey values and beliefs that can be used to explicitly or implicitly justify and promote particular views, policies, and practices.

And so, it's noteworthy to me that, again, in the context of COVID-19, where we're kind of relooking at what do we mean when we say, "health equity"? Health equity means that everyone has a fair and just opportunity to be as healthy as possible. Everyone, regardless of race, regardless of gender, regardless of age, regardless of preexisting conditions, everyone has a just, just means fair, opportunity to be as healthy as possible. And that for the purpose of measurement, because I know in your audience you may have some people there who are interested in how you measure these things. For the purpose of measurement, health equity means reducing and ultimately eliminating disparities in health and its determinants that adversely affect excluded or marginalized groups.

So, when we talk about health equity, we're focused on those populations in our country that have historically been marginalized or excluded. And while now we're talking about African Americans, Latinos, Asian, Asian-Pacific Islanders, Alaska Natives, Native Americans, these are the recognized racial ethnic minority groups in the United States. They are the protected classes in the United States. When I say, "protected class," meaning they're protected by the US Constitution. And these protections are in place because these groups have historically been seen as less than. This is why the whole Black Lives Matter matters. It's because historically black lives have not always mattered. And so, one would say if black lives matter, then all lives can matter because, finally, we're recognizing the group that has historically been left behind.

So that effort does not address poverty, that effort does not address discrimination, or the consequences of these damaging issues. People have historically been excluded. If you're not focused on them, then it's probably not a health equity effort. So, we



don't want to use the word health equity when we're talking about the most privileged group in our society. Health equity is about the least of us, the marginalized groups.

And in a society, such as ours, there should be no reason that someone is kept from achieving the American Dream simply because of the color of their skin. And while we may have had disagreements in the past about how to do that, do we do that through desegregation? Do we do that through voting rights? Do we do that through desegregating of the schools? And who could have imagined that these disparities would exist in our healthcare delivery system since everyone in that system is committed to healing disease and saving lives.

The history of racism and discrimination in our healthcare delivery system would be easy to ignore were it not so well documented. And so, it was 1985, when Secretary Margaret Heckler released the Secretary's Task Force Report on Black and Minority Health. That was the actual name of the report. And in that report, 15 volumes, the government put in one place the evidence of what they called 'excess death', that these racial and ethnic minority groups were dying before their time because of their race compared to whites.

So let me give you one example. A black woman of today is still more likely to have her baby die in the first year of life, infant mortality. A black woman with a college degree is still more likely to have her baby die in the first year of life than a white woman who hasn't graduated from high school. Now that's a data point, that's simply a fact. The reason why is why we're having this podcast today. The reason why is complex. The reason why has to do with the history of racial discrimination in our country. The reason why is that even though that black woman has a college degree, she's still black; and she's treated differently in the United States.

Even myself with a PhD, I am telling you right now that my wife wants to make sure when I walk out the door, it's almost like a flight check. "Do you have your driver's license? Do you have your," and she goes down the list, knowing that just simply

being stopped could end up with me not coming home that day. And that was going on before what happened to George Floyd. Now she won't let me out of the house at all.

**Lizette:** I don't blame her.

**Alicia:** It's a sad reality.

**Dr. Thomas:** Now in many of these minority communities, you have to understand their distrust of our healthcare delivery system is legitimate. In many black communities, there's an oral tradition where information is passed on from word of mouth. I mean growing up as a young kid in Columbus, Ohio, in the 1950s, we would travel this, deep down in the Deep South to visit my grandmother. And I remember to this day the signs on the water fountains, white and colored. And being a Northerner, guess what water fountain we kids wanted to drink out of? We said, "Is that white water really that different?"

And those were what we called the Jim Crow rules. At the ice cream shop, blacks around the back or colored around the back or Negroes around the back. No Mexicans. I remember those signs in my lifetime. In my lifetime. And so, our parents had to really kind of chastise us to follow these Jim Crow rules because bad things could happen.

And one of those bad things happened to Emmett Till. The story of Emmett Till is when he inadvertently, real or perceived, broke one of those Jim Crow rules; and he ends up dead. And it was his mother's decision to have his casket open so that people could see what was done to him when he was beaten and killed that just outraged the nation, and that was in a *Jet* magazine cover.

So my point to you is that we still live in our little bubbles; and until we can witness firsthand – it's unfortunate we have to see it firsthand, but until we witness firsthand, we sometimes don't have that action.



And now we find ourselves in the situation where we have the confluence of a global pandemic, an infectious disease, a, racial demonstration, police brutality, national conversation about race and racism, and we're all supposed to stay home and social distance, and our cases are going up.

So, we are at an inflection point; and whatever happens next, we cannot go back. I think that's the lesson. There's no going back.

And it reminds me of something that Frederick Douglass said, and I quote here, "If there is no struggle, there is no progress. Those who profess to favor freedom, and yet depreciate agitation are men who want crops without plowing the ground. They want the rain without thunder and lightning. They want the ocean without the awful roar of its many waters." End quote.

And that's what's happening in the streets right now. The awful roar of its many waters, and where we end up will determine what kind of country we're going to be moving forward.

And I want all of your audience to know, particularly those in your audience who are suffering from a disease, to recognize that their disease should not define who they are and that their disease and access to care should not be inhibited because of their age or because of their ZIP code and that they also, if they have the privilege of having access to good healthcare, if they have the privilege of trusting their healthcare professional, that they should become advocates to ensure that everyone, regardless of race, regardless of ethnicity, regardless of national origins, has that same right.

In other words, in this country it should not be a privilege. It should simply be a right of our citizenship to have access to quality healthcare.

**Alicia:** Absolutely. Dr. T., you mentioned earlier, in the beginning of this episode, your involvement with barbershops and beauty salons; and this past Tuesday you were part of a program in which you said, "We have to get comfortable with tough



conversations. We have to get comfortable with discomfort.” You said that “the goal is to disagree without being disagreeable.”

Why do you think those conversations are still so tough to have? Thousands of articles and research papers later, thousands of conversations about race and, and health disparities, I think you’re right in that we’re getting better and that we’re at a very interesting time where we’re being more upfront about the conversation. But why do you think it is that people are still so uncomfortable talking about something that could drastically and dramatically change the lives of so many people for the better?

**Dr. Thomas:** Well, I think it’s because we’ve been in denial. When I grew up, and some of your audience may be in my cohort, 1950s. When I grew up in the 1950s, young ladies, if you went into an organization where someone said, “I don’t see color. I’m color blind.” That would be like a compliment. Right.

But today, if you say that today, it’s like, “Well where have you, you know, you’re like blind.” And so, we have denied the issue of race when Barack Obama was elected President. We, actually, if you look back at those news reports, we finally have made it. We’re now in a post-racial society, and they were literally talking that way.

We are so far from a post-racial society because we have failed to grapple with, what has been described as the original sin. And that is the history of slavery and discrimination in this country.

Yes, the Emancipation Proclamation freed the slaves, but look at us. Look at us. Just a couple weeks ago we were celebrating Juneteenth. Now most people probably never even heard of Juneteenth, and literally overnight, the Chancellor of the University of Maryland says we’re going to celebrate Juneteenth. It’s going to be a holiday and let people off, starting at 1 o’clock that day.

I mean the snap of a finger, the Confederate Statue of Robert E. Lee in a very prominent place of Richmond is coming down. These are the vestiges of institutional



racism that still live in our monuments, that still live in some of our language, and unfortunately, that Jim Crow hidden in our healthcare delivery system.

And so, I think that we have held off the reckoning that comes with addressing the issue of race and racism, and that's why we're now having to deal with it.

We will finally have to face the ugly reality of racism in America; and we will finally make a commitment to solve it together. To solve it together.

And I think that COVID-19, interestingly enough, is that opportunity because COVID-19 puts us right in the heart of a health issue, puts us right in the center of having to follow science, not myths and misinformation. And the evidence is now clear that taking a science-based approach works. For those states that are opening slowly like New York and others, it worked. For those states that ignored the call, that did not take COVID seriously, look what's happening there. It's surging. The virus doesn't care. And so now we have to care, and that's why I think this is a tremendous opportunity for transformation.

**Lizette:** Definitely, I think so. And, like you said, COVID-19 is bringing this all to the forefront, and our folks, our patients, our caregivers, with cancer, there has been talk and many research studies about health disparities within the cancer population. So, this is something that we've been dealing with for a long time and studying. Now that COVID-19 has brought out these health disparities; and now that we can actually talk more about the health disparities within even the cancer realm, what can we actually do about these health disparities right now within all of the different diagnoses out there and all of the different health situations that we're dealing with?

**Dr. Thomas:** Well I think we truly do have to think outside the box because what we've been doing, even though over time we could see some incremental progress, the fact is when you begin to break out the data, whether it's cancer, type 2 diabetes, heart disease, you'll see that there's a racial difference. There's a gap. And to close that gap, we can't just keep doing what we've been doing.

And this is where the barbershop project came to life. I mean I'm a black man in America. I go to the barbershop. Dr. King used to say that the most segregated time in America was on Sunday because everyone was in church. And in the 1950s, he was probably absolutely right. But that may be less so today.

But I would submit to you that the other time that is the most segregated time in America is when we go for our personal care, when you go to get your hair done. When you go to the barbershop and the beauty salon.

And so, I'm in the barbershop and somebody walks in that hasn't been in a while, we'll call him Joe to protect him, and they say, "Hey, Joe, where you been?" Now when you walk into a black barbershop, you've got five TVs and they're all on different channels, and you've got music playing, and it's all at the same time. And everybody's talking, so it's a cacophony of what you might think is noise. And so, Joe comes in, and when he sits in the chair, he's talking to the barber about how he ended up in the Emergency Room. And they told him he had a heart attack, and they kept him for three days.

And he says to the barber, and they gave me these pills. He pulled out the pill bottle, and he says, "And the doctor told me I have to take these the rest of my life." And at this point, everybody in the barbershop's listening. Okay, music's on, TV's on, but everybody's listening. And the barber says, "Joe, you know if you take those pills, you won't be able to keep up your obligations."

Now, ladies, do I need to explain to you what that means?

**Edith:** It took me a minute, but I got it.

**Dr. Thomas:** Is there a disclaimer on this podcast? Well, let me help you. That barber, in a very subtle way, was saying you won't be able to perform sexually. Many of these blood pressure medications have a side effect of erectile dysfunction. But what struck me, for someone who had entered a hospital system, who was kept for

three days, got a diagnosis, got a prescription, was sent home, was that the look on his face, Joe is not taking those pills. Joe is not going to take those pills, and his doctor has no idea there's somebody in the community who doesn't have an MD degree who has that kind of influence.

I said, "What if, the barber would have said, "Hey, Joe, if you're having any side effects, let your doctor know. They can change up the medication. You know, talk about these things. Don't be ashamed." What if that barber was a partner? And in that moment the idea for HAIR (Health Advocates In Reach and Research), kind of was born almost 20+ years ago.

And over that time, I've written grants and tried to raise money to really bring the barbershop/beauty salon in as a partner in the effort to eliminate health disparities. Two years ago, in the *New England Journal of Medicine* was a major study, a cluster randomized trial on hypertension control through black barbershops. It was hugely successful.

And in our own work with support from the Cigna Foundation, our focus was on colon cancer. Many of you may know that the national guidelines at one point were age 50, but there was some discrepancy. The gastroenterologists said for African Americans it should be age 45 for your colonoscopy. But my point was there was a lot of confusion there, and African Americans are disproportionately impacted by colon cancer.

Here's a screening, a colonoscopy that can literally save your life. It can remove a polyp that could become cancerous. What a lifesaver. For many African Americans with cancer, the unfortunate thing is that they show up when the disease is already too advanced. It is not uncommon for African American women to be first diagnosed with breast cancer, and it's already at Stage 3 or Stage 4. Many of our therapeutics don't work as well when it's already advanced.

And so, our barbershop network was put in place to really bring the gastroenterologist into the barbershop, we weren't making these barbers second class health



professionals. We were making them advocates to say, "Talk to your doctor. Follow your doctor's orders. Let us help you follow the doctor's orders. And guess what, the gastroenterologists will be here next week to talk about colonoscopies. The pharmacist is going to come. You know, get a brown paper bag and put all the pills of your grandmother or your mother." Many people are caregivers. They have no idea what their parents or loved ones are taking. We're going to bring a pharmacist into the barbershop.

In other words, let's meet the people where they are. The miniaturization of diagnostic tools. I'm holding my cell phone right now. This means I no longer need to be tethered to a building, to a hospital, or to a clinic. I can bring advanced diagnostics out into the community, and we believe that black barbershops and beauty salons are a perfect place to establish that network.

And so we've been very, very pleased to see our barbers embrace the training. And many of them have themselves gone on to be screened, and now while they didn't have colon cancer, some have found out, guess what, I'm at risk for prostate cancer. Guess what, I have diverticulitis. But, more importantly, guess what, I like my doctor. I like my doctor. We sent them to practices that had made a commitment to addressing the needs of, of African Americans and other minorities. And so that's how I think we solve the problem.

And, the other thing is that, for many of your cancer patients, that the mere fact that they have a cancer diagnosis is such a bond that you can have a person in their 70s bond with a 15-year-old who has leukemia because that's what they have in common.

That same thing happens across race, and I'm hoping that that patient population listening to this podcast says, "Let me reach out to someone who doesn't look like me, who comes from a different ZIP code than I come from, and bond around our survivorship. Bond around our living with this cancer, beating this cancer, surviving this cancer, and not let racism get between us."

**Lizette:** I know that I had always argued, and what you said before probably is saying that my argument is wrong, and I just want to know. But I always argue that socioeconomic status is something that widens the gap between people and what they can and cannot get and in health disparity. And I always thought so more than race or ethnicity.

**Dr. Thomas:** And another thing in America is that we don't like to talk about class, so you said what you just said, and you didn't say the word class. But that's underneath of socioeconomic.

But we think in the United States, unlike Europe and other parts of the world, that we don't have class, that it's all about merit. It's all about your bootstraps. It's all about doing the right thing. Getting a job, getting an education, and doing the right thing. It's not about class. No matter, no matter how poor you grow up in America, you can make it. Isn't that the dream that we send out?

Now in the *New York Times* today, there's a chart, and it's called 'America in Black and White'; and they lay out the actual data. Now here's the facts. The evidence of racism and discrimination would be easy to ignore were it not so well-documented. And so here again let's look at the Institute of Medicine. In 1990, the Institute of Medicine released a major report called, "Addressing and Confronting Health Inequities in Healthcare." And what they did in this volume, all of the research were people who had access to healthcare. They had insurance, and it described what happened to them once they got into the healthcare system.

And one of the studies looked at people with cardiovascular disease, and they had black male and female and white male and female patients as a scenario that gave them the identical diagnosis, the identical symptoms and checklists, okay, on the chart. And then they ran physicians through this scenario to see what would happen, and here's what they learned.

That the person who was most likely to be denied appropriate diagnostic follow-up were black women. So, if you were a black woman, you were the least likely to be recommended for a cardiac catheterization, followed by black men, then white women, and then white men. So, it was a gradient.

Now you say, "Well why would there be a gradient when scientifically and biologically and based on the medical evidence it was identical and that's when they concluded, the Institute of Medicine, is that it was unconscious bias, they did not say that the physicians were outright racists. They said that there was just an unconscious bias built into our healthcare system, and that's what we needed to address. And how that was addressed through cultural competence training, some of you on this, on this call maybe have gone through cultural competence trainings. There is no way that you cannot be impacted by the racial socialization that happens in this country.

And so, here's the difference my friend and that is that the education, the income does not necessarily permit you from being marginalized. I can live in any neighborhood I want right now if I can afford it, but interestingly enough I can predict your life expectancy by your ZIP code because in America today we are still pretty much racially segregated in terms of where we live.

Racial residential segregation is baked into our system; and as a result, we don't see the other, we don't live with the other. You may go to work and see other people of color and diverse people, but when we go home, we're in more homogeneous environments. So, I mentioned, you know, a black woman with a college degree is still more likely to have her baby die in the first year of life than a white woman who hasn't graduated from high school. Now we have the socioeconomic and the race together.

Now what some of the theories are that are now being borne out is that even though I have a PhD, living in a racist society means that I am constantly under the pressure of what they call 'hyper vigilance'. So for of your audience, when they may see a police car and think, oh, I'm so glad my neighborhood's being protected, and for others they

see that police car and their blood pressure goes up because they're afraid they may get stopped. But this is how racism gets under your skin and the mechanism is stress.

So, an unrelenting stress, everyday stress, everyday racism wears black people, brown people, people of color, down in ways that impact their immune system, in ways that impact their ability to live a healthy lifestyle. And so, I'm so glad that racism now is a term I can use in mixed company and that we can talk about. And that's what I want your audience to think about that it's okay to talk about racism. And even if we disagree on its existence or disagree with what it is, that we can at least have the conversation because until we have that conversation and find a common way forward, we will be here again. And I think the death of George Floyd, now think about it, that death took place not in Mississippi, not down south in Alabama; it was Minnesota. And on any ranking, any ranking, the Robert Wood Johnson County Health Rankings guess what is the number one healthiest, happiest place in the United States. Minnesota. And the governor of Minnesota had to come out and say, "Yes, we rank number one in the happiest place in the country. We're number one in quality of life, but only if you're white." I thought it was so important that he said that, that black Minnesotans do not experience that same joy regardless of their socioeconomic status.

And so, I think that's why this really took off. Most people in the north do not believe they're racist. They did not have Confederate statues in Minnesota. They did not have all these vestiges of racism, and yet it happened there, and George Floyd's death was but a spark in the dry grass of racism in this country. And look what happened. It went not only across the country; it went around the world. The largest demonstration for Black Lives Matter outside of the United States was in Germany. They were marching with Black Lives Matter signs in Australia. This is unbelievable transformative change we're going through right now.

**Alicia:** Dr. T., an article entitled, "Health Disparities: The Importance of Culture and Health Communication" written by yourself and two physicians, Dr. Fine and Dr. Ibrahim, it mentions that the root causes of health disparities are numerous and relate



to individual behaviors, provider knowledge, attitudes, organization of the healthcare system, and societal cultural values. It goes on to mention that the efforts to eliminate health disparities must be informed by the influence of culture on the attitudes, beliefs, and practices of not only minority populations but also public health policy makers and the health professionals responsible for delivery of medical services and public health interventions designed to close the health gap.

I think about a interview that Serena Williams did, and she could afford any hospital that she wanted to go to. And even her experience of giving birth she mentions how, doctors didn't believe what she was saying. She mentions how she was in so much pain that she kind of had to show them that what she was saying was backed up by what she was feeling. And she went on to say that I know for a fact this would not have been the case had I been a white woman because her word would have been taken. And I think that's very important to mention and it highlights what you were saying earlier that, you can have all the money in the world, but if you have that unconscious or conscious bias infiltrate the entire situation that can lead to what we've seen, deadly outcomes.

**Dr. Thomas:** Indeed, and Serena Williams is a very good example. And you should know that many of my African American graduate students or female graduate students were just so taken aback. When they heard what we're all talking about now cause they all want to have children, they're afraid. They're so afraid. And so her case I think is a very good example of the intersectionality because when you take off your uniform, be it a tennis player or be it a lawyer, and you put on that hospital gown, guess what, you are stripped of a certain amount of your identity. And even the white patients probably feel a little bit of that, but they simply have more agency.

When that doctor comes in, I mean he could be your cousin, he could, you know, and they feel like there's some connection. But when the person is, you know, of a different race, different background, that same human connection may or may not be there. So, training of the health professionals is very important. And so, again, when



physicians or other health professionals say, "I don't see race, I just see the patient chart. I just see" And guess what, that's not enough.

Here's what we've learned. That if you consciously try to say, "I'm color blind, I don't see race," it's, you ready for this, you're more likely to commit biased errors. You're more likely to commit acts of discrimination by actively pushing out of your mind that race matters.

It is by acknowledging that race matters, by acknowledging, "I've never had a black teacher in my educational career. I've never had a black roommate. I've never lived around black people or Hispanic people or Asian people." By acknowledging that, you're more likely to be sensitive to the unconscious bias, the slights that are taken as forms of discrimination.

And so we went through a whole period of trying to be color blind and thinking that was the value and that was the thing to do, to recognizing, no, we don't want to be blind at all. We want to be inclusive. We want to see the strength of our diversity and be inclusive and learn about other people's lives.

And the other lesson for those who thought, well, we'll just grow out of this with future generations, all you gotta do is look at what's happening that you even have young people in the country who are part of that white supremacist activity. But it is the diversity of the demonstrations in the street that gives me so much hope. I'll never forget the sign I saw of a young white kid. The sign he was carrying said, "Black power." And it was perfectly okay.

I do believe we've made progress, but I do believe it has been too slow, and that to think of the police in one community as protectors and to think of the police in another community as a military occupation, should not happen in our country. And so, we as citizens have to talk about that across those different perspectives.

**Lizette:** Sure. As well as the healthcare. Alicia's bringing up and you're bringing up the disparity in healthcare. And I think it's important that doctors are also trained about unconscious bias because if you don't know that there is unconscious bias, then how can you actually help yourself try not to have that type of bias?

**Dr. Thomas:** We have interviewed physicians in the Emergency Room when they see all of these, violent cases coming in and some of the comments that are made are very disparaging. And even though they're healthcare providers, they're under a lot of stress and maybe it's gallows humor or something, but it plays out along racial lines. And I've heard young residents and young medical students say they heard, you know, racist comments from the senior physician trainer. So, if the leader is modeling that, it filters down.

I do not think that the so-called mandatory culture competence training, which many of them do online, like you're taking-

**Alicia:** Oh!

**Dr. Thomas:** -a quiz is sufficient.

**Alicia:** That is how I feel.

**Dr. Thomas:** Yeah, it's like, "Okay, yeah, I did, I did my quiz. I know exactly how Latinos work." And so, it is important, but it is insufficient. And this is why we think that in my work bringing health professionals into the barber shop-

**Lizette:** Yes.

**Dr. Thomas:** -for many of them they had never ever, ever been in a black barber shop. You should see their faces. I mean we have video of them, and they love it! They love it! They say, "I'm finally meeting people I've been trying to get into the hospital I'm meeting them here." But they're also learning what they don't know. They're learning what they don't know. And unfortunately, the way their education is

structured, they only have like, you know, two weeks of what they call social medicine and then it's all over. So, hopefully, what we're experiencing right now will change some of that.

Do any of you ladies like pancakes? I'm sure your audience out there listening they love pancakes.

**Dr. Thomas:** What kind of syrup do you use in your house?

**Alicia:** I don't have Aunt Jemima in my house.

**Dr. Thomas:** Aunt Jemima and Uncle Ben have been set free at last! Free at last! Thank God Almighty, they're free at last!

What your audience may not know is that Aunt Jemima as a brand went from a black slave mammy on the syrup to the middle class black women you see on your syrup bottle today, it looks like she shops at Macy's. But it is nonetheless part of that racial trope. So we have Aunt Jemima, Uncle Ben; you got Frito Bandito. I mean now these companies are looking at how they've used racism and racial tropes to sell products. And we have bought those products, we have bought into those products. And now what they're saying is what? "You know what, we have to acknowledge we're wrong. We were insensitive," you know. "Many, many, many years later we just thought it was done this way. We're going to acknowledge it was wrong."

Columbia, here at the University of Maryland, we have a system, the University System of Maryland and administratively we have a Board of Regents that kind of operates the whole system of Maryland. Columbia University, the equivalent of their Board of Regents, you know what they called it? It was called the Board of Overseers. And guess what? In this moment that we're in right now they said, "We're changing the name. We're no longer going to be the Board of Overseers."

The NBA, they have what they call owners, right, NBA owners. These are very, very wealthy people, the owners, and they have these teams that are, 90% black. Guess



what? NBA is dropping the word owners. Subtle. Words matter. Words convey values. Words convey meaning. And so, for those African Americans who just swallowed and just took it as, what are we going to do as they poured their Aunt Jemima syrup – I love Aunt Jemima. I'm a little bit sad, I'm going to miss her on the bottle. But some of my black friends say is, "Oh, we only had Log Cabin in our house."

So, we're now stripping away these hidden forms of racial discrimination, these hidden ways that we always let black people and other minorities know you know you're really less than. And I think that's a good thing, but it cannot just be window dressing. It cannot just be I retire, I set free Aunt Jemima and Uncle Ben, but my board of directors is all male or my board of directors is 99.9% white. We have to now hold them accountable to real change, structural change, so that we can move our nation forward.

**Lizette:** Definitely. And we also want to thank you for bringing healthcare and health awareness into the community cause, you're right, people trust barbers, people trust beauty shops. It's not just going in, getting your hair cut and going out; there is that social aspect that you're talking about, and that's where the trust comes in.

And we really do want to thank you because our Myeloma Link program is going there. I mean we're going to be right there with you educating African Americans and black Americans about myeloma. Myeloma is a blood cancer, but it has twice the incidence in African Americans than it does have in white Americans, especially African males. And people are more likely to not get the latest treatments and not get treatment as early as their white counterparts.

So just being able to talk about it talking about, what somebody might experience because doctors aren't always looking for myeloma as their first thing. You have to rule everything out first because it's not the most common type of cancer. But at the same time just, making people their own advocates and knowing what to look for I think is something really powerful, especially if doctors aren't looking, for things. And,

of course, your part of your own treatment team because you know your own body, so you know when something is wrong. So, thank you for that because that's really helping LLS get to more folks, get to more people and, hopefully, have people get better treatment options.

**Dr. Thomas:** Well I am so glad to have you as a partner. And in December before we had to all shut down, we hosted a workshop here in Maryland and it was, it was the title of workshop, "What black barbers and stylists say to scientists, 'No research on us without us.'" And Myeloma Link was a partner and we had two African American men who were survivors of myeloma and they talked about how they had never heard of the disease before and now they're out being advocates and dispelling myths. And they, they said, "We love to come into the barber shops and educate people so they're not afraid of this." And I'm thinking as we're talking right now, what an opportunity to get a buddy system where we not only bring people together because of the commonality of their common disease but bringing them together across these lines. Have an African American myeloma patient with a buddy who's a white myeloma patient. Do those kinds of things. They bond around survivorship but together they can address the issues of race.

**Lizette:** I think that's a great idea. I know that we're also starting our Latino outreach. You know, we're working more closely trying to work with Latino and Hispanic populations. We do have Latino children more likely of getting acute leukemias and non-Hodgkin lymphoma is the fifth most common cancer in Hispanics. So, we are trying to also make sure that we are inclusive. I know The Leukemia & Lymphoma Society over the years has tried to reach out to a lot of rural populations, a lot of indigenous folks where care is really hard to obtain, especially cancer care for those folks. And, of course, we have people that are undocumented that may not get healthcare might not be as available to them. So, a lot of issues.

**Dr. Thomas:** And on the science side, it's very important that these cancer clinical trials are now more diverse. And, and you can't do that unless you build trust with

these communities and we hold these comprehensive cancer centers accountable for diversifying their research study populations.

Again, this is a moment. This moment is not just about police brutality. This is the confluence of all those things. And we in healthcare are not immune. We are not immune. And there have been stories in the COVID cases where African Americans have wanted to get tested, they've been refused testing. In other words, their words weren't listened to and people have died, and they think, oh, if I was white, I would've gotten a test. That may or may not be true, but they believe it's true and that's what we have to prevent.

**Alicia:** That's a great point. And, doctor, I think what you mentioned earlier and throughout this conversation is the importance of having the science behind what we're saying, you know, the metrics behind what we're saying and also just having a conversation now present day cause I know a lot of times and when we hear African Americans or black people and distrust, a lot of people's minds go automatically to the Tuskegee Syphilis study. That study was one of the longest nontherapeutic experiments on human beings in medical history so it carries that weight, but I think it's still important to have the conversation about what's happening present day to let everyone know, patients, caregivers, physicians, policy makers that this is still happening and it's happening with present day people with present day issues.

Like you said, it's hopeful to know that things are changing. But I also think it's important to just mention that a lot of times we separate the past from the present and a lot of it is blended and a lot of it just needs to be discussed and addressed.

**Dr. Thomas:** They gave this quote to Mark Twain, "The past is not the past. The past may not repeat itself, but it rhymes." And so, yes, the Tuskegee, the Tuskegee Syphilis study is like the quintessential example of research abuse. Forty years-

**Alicia:** Yeah.

**Dr. Thomas:** -1932 to 1972, and one might think that it's over, but it is not.

**Alicia:** Right.

**Dr. Thomas:** And so, this is why the training of health professionals is so important. Many physicians in their training have what they call simulated patients where there's an actual, these are actors that come in with symptoms. They act out the symptoms and they help the doctor, you know, practice their bedside manner.

At a time when we're going through right now with stay at home, I think we may need to even think even more creatively about how to train not only physicians but others using simulators. In other words, imagine this for me. Right now, if you're an airplane pilot, you get trained in a simulator. You, you get in this thing and you fly a plane. You take off, you land as if you're in a real plane but you're in a simulator.

Well, the technology now allows us to have avatar simulators actually simulating a human interaction. And imagine that you could go into a simulator, I mean you, let's say you did your online cultural competence training and now we're going to put you in a simulator and you're going to practice interacting with an African American patient or a Latino patient or someone who is low literate or someone who's poor, and you could practice without hurting anybody. You know, you could practice without being reprimanded by your supervisor.

I think we have to be much more creative about the training and push back against, the, the health professional schools that say, "Our curriculum's so tight we don't have time for that. It's all about the science." Well, you're not going to get to the science if you do so in ways that are so-called color blind. We have to make sure that the socialization of our healthcare professionals does not bake in the existing bias that's already in the society.

And so, we have been working with a group called Mursion, Inc. out in California with a human simulator. And I'd love to be able to come back on your podcast and talk



about what it means to work in a simulator as a way of addressing health disparities, as a way of addressing one's own unconscious bias and take a few, young scholars with me and actually have you experience the simulator and then come back and talk about it on the podcast. Wouldn't that be awesome?

**Alicia:** Awesome!

**Lizette:** That would be awesome.

**Edith:** Yes, that would be.

**Lizette:** That would be cool.

**Edith:** Would the simulator be able to pass or fail?

**Dr. Thomas:** See, so it, would be, we used to call that one a criteria. In other words, you just come back as many times as you want until you get it right. But many, so many health professionals, for example, if they hear a patient talk about Tuskegee or talk about their fears and they say, "Oh that happened so long ago," they need to understand how that reads. That means that you don't understand my people. You don't understand what my people have gone through. And if you don't understand that, how can I trust you?

So, we help health professionals become more comfortable with what we'd call contentious conversations. How to have those contentious conversations and still be friends, still have relationship, actually use those contentious conversations to build trust.

**Edith:** Definitely. Dr. T., how can we as a society address the issue of health disparities effectively?

**Dr. Thomas:** Well, I think we're doing it right now. When I reached out to your organization, they were right on board to cosponsor the black barber shop workshop, What Black Barbers and Stylists Say to Scientists. They joined Advancing Cancer

Treatment. That was our primary sponsor, so there were two cancer national organizations that sponsored the workshop, so I think that's a start. I think the next thing is we've come up with a very interesting innovation in our barber shop network; it's called the barbershophealthbox. So, you millennials out there in the podcast audience, if you have an Instagram account, go search for the @barbershophealthbox, no spaces, and see what we're doing.

So in the barber shop, we have a mailbox wrapped in the colors of a barber pole with a pen and an index card, and the barbers or the clients can write any question down they want about health and drop it in the box. And my grad students come and pick up the mail, so to speak and they turn those questions into infographics for low literate populations – images, pictures. And you can see some of the infographics that have been created.

So, while we're in the shops recognizing there's a high risk for cancer in this population, sometimes you can't start there. Sometimes you start with, "What questions do you have?" And so now who would imagine somebody's going to drop in the box about acne, somebody's going to drop in the box about erectile dysfunction, somebody drops a question in the box about CBD and marijuana, and then somebody drops in the box a question about prostate cancer? You gotta wait till there's enough trust, meet them where they are, and then build the relationship. Can you imagine Myeloma Link having a dedicated TV channel right there in the black barber shop? That would be awesome. And that your patient population telling their story, their personal story, be they black, white, otherwise. And having those personal stories be shared in the barber shop and beauty salons could really inspire someone, could really take away the fear that people have and break down some of the myths and misperceptions. So, that's what we're trying to do and expand around the country, and so that's a way that we would continue to work together.

**Lizette:** We will definitely get there, Dr. T. How about for us folks that aren't millennials and don't have an Instagram account, how could we engage?

**Edith:** Smoke signals. Smoke signals.

**Dr. Thomas:** So, you know, we've done Facebook Live. I think that should be our, one of our next things that we do together, let's do a Facebook Live Zoom session like we're doing right now and, and bring on the barbers, bring on the, the patient population and have this conversation more broadly. I think you need to be not see what's happening in the demonstrations as something separate from what we're about, that the health message around cancer prevention, cancer disparities should be part of the same conversation we're having around police brutality, structural racism, institutional racism. And so we should have some signs up saying, you know, "Let's close the myeloma disparity gap out there along with Black Power and Black Lives Matters." There are a number of ways that we can be part of this conversation and raise awareness that these issues spill over into our healthcare delivery system and be present. And, what you're doing right now I don't know what the other topics have been in your podcasts, but I'm, presuming that this may be one of the first where we're talking explicitly about issues of race, racism, and structural determinants of health. We should just do more of it.

**Alicia:** Absolutely. Dr. T., I'm going to put you on the spot. Are you ready?

**Dr. Thomas:** Sure! Sure!

**Alicia:** So, on our website we have a saying that says, "After diagnosis comes hope." If you were to finish that sentence based off your experience, what you've seen, how would you finish that? "After a diagnosis comes," what would be that word for you?

**Dr. Thomas:** Well after a diagnosis comes the reality check. I think for many people after the diagnosis, it's like-

**Alicia:** Yeah.

**Dr. Thomas:** -I need to take my life more seriously. I should not take things for granted, that the relationships in my life are actually important. My family is

important. In other words, they begin to face their own mortality. But they also need to know that after that reality check does come hope because cancer is no longer a death sentence.

I'm old enough to remember where the word cancer was like a death sentence. And you have to understand in many minority communities there's a belief that if you say something you give power to that thing. So, it was not uncommon for me to go into a cancer support group on an issue like breast cancer and not see any African American women in the support group. And I was always curious about that. And you'd meet in the hospitals and there would be a lot of white females. And so, in exploring that I learned that –and some of this is part of, was faith, traditions, and religion of the belief that if I say a thing I give power to that thing. Other cultures say, "If I say that thing, I can control that thing." And I think that may be a subtle, subtle difference in terms of a group. So if you put up a sign that says, "Cancer support group," black folk ain't gonna walk through that door.

So, what we did is, again, reframe our whole initiative that we launched, and this pitch was in the city of Pittsburgh. We called it 'The Healthy Black Family Project'. And guess what, people showed up in droves! Eight thousand people signed up, 'The Healthy Black Family Project'. And guess what they came with? They came with all their burdens. They came with all their diseases. They came with their diabetes, their obesity, their cancers, but we didn't call it that. So, I think some of it is a bit of reframing.

The other is knowing someone who's a survivor. We don't talk about victims; we talk about survivorship. And I think that's one of the big values coming from the cancer world, many of the people in your podcast audience are survivors. They feel like they are in charge, they are empowered, like that in some cases the diseases itself may have made them better people. I love to hear from them that they love their family more. They took time to build relationships more because they recognized their own mortality. So, we need to let people know that there is hope, but they don't know that

if they don't know anyone who looks like them who has survived. So let's give voice and the image.

When you told me about myeloma and that African American men, in particular, are disproportionately impacted, I would say I had never heard a black person ever say the word myeloma - how is that possible? Until I was at the workshop where you had two of your survivors come and tell their story. They told their story to an audience full of black barbers and stylists and those people left inspired to tell their clients. That's how we do it, each one, teach one and be consistent.

**Alicia:** Absolutely. Dr. T., is there anything that you feel that we didn't cover today that you think is important for our audience to hear?

**Dr. Thomas:** We've done work, and we're trying to figure out why are African American women are not coming back for their mammograms or even after they have a diagnosis and treatment, not coming back for support? And we did interviews with them, and we found out that they did not believe that the cancer prevention message was for them. And we were stunned because we're talking just, you know, three, four years ago. You would think there would be nothing new to learn. And so I think we shouldn't take for granted the need for giving a face and a voice to a debate that we have.

And so, one of the things that we've done is, again, using cultural tailoring, we've developed what's called the Underground Railroad Bicycle Route. If you Google that, you'd find a 2,100-mile bicycle route that begins in Mobile, Alabama, and ends in Owen Sound, Canada. And so, we use the Underground Railroad, black history, as a way of getting people more physically active and getting them involved in the whole biking and cycling community that I did not see many African Americans participating in.

And so, I think using black history to connect to the very lifestyle behaviors we want people to adopt. The other is to recognize that this is a catastrophe, and it should be treated as other catastrophes with an adequacy of resources. That's both the danger



and the opportunity. The danger is to assume that these disparities are simply baked in and that African Americans are simply destined to live sicker and die younger. We cannot let that happen. And the conversation we're having in our country today gives me hope that we are not going to let that happen. That we're going to turn the chapter and start a brand new one together.

**Alicia:** So well said. We couldn't agree more. Dr. T., thank you so much for joining us today and for such an insightful conversation. We believe that change happens with the intersection of conversation, education, like you said, resources, and accountability. And we're happy that we're able to converse with you today about such an important issue.

We are hopeful that things are changing, especially with the work that you're doing. And here at LLS, we are certainly doing our job to bridge the racial gap and the impact racial and ethnic disparities have on blood cancer patients and patients overall. So, thank you so much again for joining us.

**Dr. Thomas:** You give me hope. Thank you.

**Edith:** Thank you.

**Lizette:** You give us hope. So, thank you.