

THE BLOODLINE WITH LLS

A PODCAST FOR PATIENTS AND CAREGIVERS

Episode: 'Addressing Racial Health Disparities Through Community Outreach'

Description:

Join us as we speak to Dr. Lorna McNeill, a Professor and Associate Director for Health Disparities and Community Outreach at MD Anderson Cancer Center in Houston, TX, along with a special guest from our LLS Patient and Community Outreach team, Erika Pomares. In this episode, Dr. McNeill shares how people of color, particularly African Americans, have disproportionate rates of cancer incidence and death, but are also more likely to face racial bias in healthcare and clinical trials. She offers potential solutions to improve the healthcare outcomes for these underserved communities. Dr. McNeill and Erika also discuss the importance of community outreach, and how programs, like LLS's Myeloma Link, have improved access to care and trust in the medical community.

Transcript:

Elissa: Welcome to the *Bloodline with LLS*. I'm Elissa.

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

Elissa: Today we will be speaking to Dr. Lorna McNeill and special guest from LLS, Erika Pomares.

Dr. McNeil is a Professor and Chair of the Department of Health Disparities Research at the University of Texas MD Anderson Cancer Center. Her research focuses on the elimination of cancer-related health disparities in minority populations with the objective to better understand and design innovative solutions to address health inequities in racial and ethnic minority communities.



As Associate Director for Health Disparities and Community Outreach at MD Anderson, Dr. McNeil directs the Center for Community Engaged Translational Research, which works with MD Anderson faculty to develop collaborations with underserved communities, with a focus on conducting high quality relevant cancer prevention research.

This research takes place in minority and underserved communities such as public housing developments, black churches, community-based clinics and low-income neighborhoods which are often communities with excess cancer death rates.

This setting is where her team has worked with our colleague, LLS Senior Patient and Community Outreach Manager, Erika Pomares. As a licensed social worker, she has worked with Dr. McNeil's team partnering on various educational programs for cancer patients in the local underserved and minority communities over the past 15 years.

In her role with LLS, she works on community outreach with family support groups, with individual patients on their specific needs, as well as manages educational sessions for cancer patients.

Welcome Dr. McNeil and Erika.

Dr. Lorna McNeil: Thanks for having me.

Erika: Thank you.

Elissa: So, let's start with learning a little bit about you, Dr. McNeil. How did you get started as a public health researcher, and what drew you to the cancer health disparities research?

Dr. McNeil: So, I was finishing up my undergraduate degree at University of North Carolina Chapel Hill, a little wayward at that time trying to figure out what I wanted to do next because an undergraduate degree doesn't necessarily mean you have a profession, or you know what you want to do next.

Elissa: Right.

Dr. McNeil: And it was around that time that some students from the School of Public Health reached out to me - I worked at the Black Cultural Center at UNC – and they wanted to organize a blood drive to try to get more African Americans to donate blood.

And so, in terms of putting on this blood drive focused on African American students at UNC, I discovered what public health was. Didn't know what it was. I knew medicine and what that was but really didn't have an orientation to public health. And so unbeknownst to me the number one or number two school of public health was right in my backyard on that campus. And so, I applied to the school of public health, I got in, and from them I've been hooked on public health. It's been a deep meaningful calling for me once I discovered this field of work.

So, I got my master's degree in Public Health. And then I started to kind of get a bug for research. I was curious about why things were occurring in a way that I didn't think that way before. So, I started working on a research project where we were talking to pregnant women who had just given birth and they were smoking. They were trying to get them to stop smoking during pregnancy and to remain, quit after they gave birth. And I really started to understand what their life experiences were like.

As a research assistant, my job was to call them and ask them a series of questions about whether or not they were still smoking. And these were predominantly white and rural women. And what I learned was people's day-to-day experiences, even though they hear the prevention messages, are unable to really sort of activate to that in their lives given some of the other things that they were dealing with.

And so that was my first entrée into disparities particularly, and then I focused on cancer disparities because it was a focus on tobacco. And so then ever since then I've

been working on various research studies and with various communities and populations to reduce their risk for developing cancer.

Erika: So, our podcast today is on racial health disparities in cancer. Could you share with our listeners what the data shows in health disparities related to race and ethnicity in America?

Dr. McNeil: So African American men have the highest rates of getting cancer, so cancer incidence, as well as the highest rates of cancer mortality or death from cancer. So above all race and ethnicities and sexes, the burden is more stark for African American men.

White women, while they do get cancer at higher rates than all racial ethnic women, black women are the one who die from cancer at higher rates as well.

And then for Hispanic and Asian Americans and other populations, you have various cancers for those groups where they may have higher rates than other groups. So, for example, liver cancer is on the rise in Texas, and that is primarily being driven by increases in Hispanics, primarily Hispanic men, who drive that higher incidence of liver cancer in Texas.

So, depending on the cancer, you'll see higher rates in other racial ethnic minority groups but, like I said, black men have the highest incidence and mortality rates.

Elissa: Now I'm sure that many of our listeners might not have been aware about the higher blood cancer incidence and death rates in people of color.

As an example, *Medical News Today* wrote an article earlier this year that discussed a study that showed how black patients with acute myeloid leukemia, or AML, have an 11% lower survival rate than white patients, which is pretty significant considering the overall 5-year survival for AML was only about 29% at the time of this 2018 study. In addition, we also know that black Americans are more likely to be diagnosed with multiple myeloma.

Do we know why this is happening?

Dr. McNeil: It does exist and I know that there's, at least at MD Anderson, a good colleague of mine, Chris Flowers, who chairs the Department of Lymphoma/Myeloma have great science trying to understand why there are disparities there, but on my side of it, is to try to help more African Americans participate in clinical trials that would improve their chances of survival from the cancer when they do get it.

Lizette: Sure. And doctor, let's talk about clinical trials for a moment. I know that at LLS we really encourage all patients to talk to their doctors, to their treatment teams about clinical trials as a potential treatment. Now there can be a real hesitation in black communities as well as other minority communities to join clinical trials due to the history of medicine in America. What is it like now for people of color participating in clinical trials? Are we really seeing health disparities in the clinical trial setting?

Dr. McNeil: Absolutely! So you'll see health disparities in almost every aspect of health and medicine due to the nature and the structure of these systems that were not necessarily built for diversity, right. Most of our history of clinical trial participation was based on white males who were the basis, a lot of the early discoveries. And so once you have that kind of history for who participates in trials and what we know about disease and the outcomes, we're really, basically, as a society playing catchup trying to get more people to participate.

NIH (National Institutes of Health), for example, recognizes that this is a problem and has mandated that women need to have equitable participation in clinical trials. And, of course, now the racial ethnic minorities have to have equitable participation in clinical trials. So, now there are lower rates of participation for racial ethnic minorities and there is even some evidence that that participation may be declining, over time.

So this is a really important topic and a really critical area for us to be developing research that helps us better understand what are the reasons for lack of participation? And then, scientifically, what kind of interventions can be done to address that and

increase that participation? And I can share a little bit more about what some of the drivers of lack of participation are, but, yes, there are disparities in participation as well.

Lizette: Sure. We don't have the real-world data. We don't know what's really going to go on if our clinical trials are based solely on one population, right. And, also, you did mention I think that just because of history, a lot of our underserved communities, a lot of our minority communities are hesitant to actually go on a trial because of how people were treated in the past.

Dr. McNeil: Correct. We see clinical trials as lifesaving treatments or lifesaving alternatives or what we learn from participating in a trial may or may not benefit that person right now, but it definitely benefits people in future generations. But, when you are experiencing a cancer diagnosis, you want to know how can you improve your chances now? What is that best treatment? And for many people in general, not just racial ethnic minorities, it feels like standard of care is the safest route to go.

Of course, standard of care is based on research, too, right. But it's over time we've developed that research that says this is the appropriate treatment for this particular diagnosis. And then a trial seems more exploratory. It seems like we don't actually know what we're doing. We're using people as guinea pigs to test out things and that it's not safe.

Now, of course, what we know is clinical trials are extremely safe. That by the time it gets to humans that participate in research, many of those safety issues have been taken care of. And, yes, there are some Phase I trials where we are trying to understand the toxicity, but these are conversations that patients should have with their physicians in terms of what's the right trial for them. But, historically, because of racial injustice and actual outright discrimination for African Americans; there's the history of Tuskegee where African Americans were absolutely used as guinea pigs for that particular trial to see what was the natural end and progression to syphilis, that

there is still this distrust that we see among African Americans, specifically, within the healthcare system as well, and it lends itself to this participation in clinical trials.

However, I will say that overall, I see, like you said, that the data is still sparse to be able to really determine that. But an increased interest, an increased willingness to participate in research, what studies show is that one of the major reasons why minorities say they don't participate in a trial because they weren't aware that there was a trial available, and no one asked them to participate.

Now those are structural barriers to participating in a trial, meaning that starts with the research team, and that starts with the research infrastructure. That starts with how do we make patients aware of trials? Is that in a systemic way where every patient is offered an opportunity to participate in a trial, or are we selectively deciding who we approach to participate in a trial? And if so, is that based on our own biases of who we think is most likely to participate in a trial, and so, inadvertently we are reducing the likelihood of minorities to participate because we're not offering trials to people in a systematic way.

So, yes, patients have the right to refuse participation in trials and we need to work with reducing those barriers that they may have personally, but there are also lots of structural barriers that exist that, really, before a patient can even decide if they want to participate in a trial, if one isn't offered to them or they're ineligible for those trials, then off top, they can't even decide if they want to participate.

Elissa: So let's talk a little bit about those structural barriers, let's talk about professional bias in healthcare. You just mentioned an example, but we also know that across the board for various diseases, cancers, other ailments, people of color can tend to get worse outcomes or even delayed treatment. And we interviewed a young adult lymphoma patient for the podcast last year who shared that she had had issues with doctors not believing she was in pain and even didn't give her Tylenol® to reduce

a fever. And we know that neutropenic fevers in blood cancers can be very dangerous.

So it seems that professional bias is a real issue. What are you finding in your research about that, and what can be done to improve this?

Dr. McNeil: Bias can be implicit or explicit, right. Implicit I think is probably the majority of the type of bias that we see where we have certain preferences for people who look like us, people who seem familiar to us. There's more of a natural connection and relationship to people who look like us. That's for each and every one of us.

Well, if most of our clinic staff and our research staff are, for example, white Americans, then there's going to be this natural bias towards that group of people and less inclined towards others that don't look like us.

And then, of course, there are explicit bias where people are intentionally discriminating against people of color. Also discriminating against people with disabilities, discriminating against people without insurance or people who are experiencing poverty or homelessness; the list can go on and on. That we also tend to have policies that explicitly discriminate against those people. They aren't able to get treatment. They aren't able to have access to the things that people with insurance have access to, for example.

And so the research shows that both of those types of biases, both explicit based on policies and in personal explicit bias, right, where we are then taking that bias that we have towards a group and then demonstrating that outwardly that that exist in healthcare absolutely. But for most of us, and that's for everybody, that we have these implicit biases that also can achieve that same effect unintentionally.

And so there's a great movement; it really started years ago, it was cultural competency training is what it was called many, many years ago. And that now in

more recent years, that type of training and understanding that exists within the healthcare system, it is a fact. It's not something that's debatable, and then because it's a fact, it's something that we need to address. I think healthcare systems are taking a more serious approach to reducing bias in healthcare.

Elissa: It is a little bit of an uncomfortable conversation sometimes isn't it, when you're talking about particularly implicit bias that I think, you know you said it wasn't a debate. We know that this happens, and people still don't want to believe it, they don't want to believe that this is a problem that it's out there. I mean, how do we deal with that?

Dr. McNeil: That's a hard question to say because if you're waiting for people to personally have some deep feelings about it, then, yeah, that can take a long time. And so instead, what we do is we mandate it. As a healthcare system we say there's no room for this bias to be in our healthcare system. We do not want it to negatively impact patients. Because it's a fact, we're going to do something about it. And that tends to be in the form of mandatory trainings that are required for people to do. No different than we care about safety. Everyone's job is to be concerned about the safety of patients and, annually, you have to undergo safety training to make sure that we are not harming patients. This is an equal harm that is occurring that, just like safety, you're not trying to hurt someone by having unsafe practices, but that might be the way you are used to doing something and now data shows that that kind of practice is unsafe.

Bias is a similar kind of approach that is necessary to take that is not up to whether or not someone wants to believe or understand personally whether or not that they have a bias. But once you go through these implicit bias trainings, we all are awakened to the fact that all of us experience this. As a black woman I have bias against other people unconsciously that dictates how I move and how I talk to people, and how I interact with people. And from a personal growth perspective, we should all want to know that we're doing that and want to not do that.

But if, personally, from a growth perspective, you're not necessarily interested in that, the healthcare system should mandate that. We remove that to the extent that we can.

Erika: Thank you so much Dr. McNeil for sharing that. Elissa mentioned in the introduction about your community outreach work which is amazing. Could you talk a little bit of what you have done in the community and what you are doing?

I know that we're in pandemic COVID world. Maybe right before COVID, what were you doing and what have you all been doing virtually?

Dr. McNeil: My approach to disparities and eliminating cancer disparities, is recognizing that you have to engage the people in which you want the research to benefit, right. So it has a strong community engagement approach and a strong partnership approach to the work that we do. So whereas I might want to focus on, as a scientist I do physical activity interventions in African American and Hispanic populations. Want to figure out ways to increase physical activity to reduce their risk for developing cancer. But I'm only so good at developing those interventions if I don't engage these particular populations and communities in the research that I'm trying to do.

So they let me know, yes, this is a good strategy. Yes, this is a good approach. No, we've done that before. Or no, people are unlikely to want to do it in that way. They let me know whether or not I turn right or turn left with the type of research that I do to make sure that it's as relevant as possible to people. When you make the research that you do relevant to the population that you want it to benefit, you will see increased participation from those groups.

So, from my perspective, community engagement is foundational to being able to really think about and be intentional about eliminating cancer disparities.



So with that I direct a center for community engaged translational research, and one of the things that we do on behalf of MD Anderson is develop these strong relationships in the communities with different racial ethnic minority populations and all kinds of different groups, rural populations as well, for example. And then with different organization like yours as one of them in order to have that research/community partnership in order to advance the science and research.

So I do a lot of research and work in faith-based communities. I've been working with African Americans through churches for probably 16 years here in Texas. But then in my training in North Carolina that I mentioned, I started doing that, so for well over 25 years or so have I been partnering with African American churches.

And so that work continues. We continue to develop new partnerships and new relationships with organizations in the community. Many of these partnerships are with folks that don't even do health related work as well. So like you might say a church, for example, or other kinds of organizations where their mission is something else. But they have strong relationships with the communities, so you want to partner with them. For example, 100 Black Men of America. I just mentioned that African American men have the highest incidence and mortality rates of cancer. And you want to partner with black men in order to identify what can be done to reduce their rates of cancer as well as improve their treatment outcomes. Well, you want to partner with an organization that has access to those men so that you can figure out how to design an intervention in the right way.

So like everybody during COVID, we've all been pivoting to online ways to engage minorities as well as other community organizations and partners. And there have been some pluses from that. We've all kind of gotten to learn Zoom platforms, and there are sometimes where you have, at least early on, increased participation from some community partners because it's more convenient to do a podcast, like we're doing now, from my home, right.

Erika: Right.

Dr. McNeil: Instead of having to physically come in, worry about childcare, make sure you're feeding people and having enough money to be able to do that. The longer this pandemic goes on, the longer we'll see whether or not that engagement continues and whether or not people are starting to crave traditional ways in which we would engage people before and, therefore, need to maybe do more of a hybrid model. This online kind of virtual world is going to work for some groups, but then there are others that to engage them it really needs to be an in-person, one-on-one relationship building process.

Erika: I agree. And for each of our organizations we've have some very unique areas of expertise around cancer education and outreach in the community. And I have been proud to work with your team in the local community over the last 15 years doing various education topics and clinical trials. We've done so many programs over the years, educating the community about clinical trials.

We partner to also increase awareness about other cancers like prostate cancer that have a high incident rate in black Americans, like myeloma.

So we've really been joined at the hip making sure that we educate the community in general about cancer awareness and updated treatment options.

It was also mentioned that Black Americans are diagnosed at a higher rate than any other race, particularly with multiple myeloma, so our community outreach program that we have at LLS is our Myeloma Link program, which we are increasing the awareness of myeloma in the black community and, also, to make sure that they know about the up-to-date treatment options in clinical trials and resources available to them.

And so prior to the pandemic I was able to speak at your church health conference about Myeloma Link for a breakout session, and just so grateful for that opportunity to share that information. Any time we can get the word out about myeloma.

Dr. McNeil: That church conference was a great opportunity to bring together African Americans, faith-based organizations, other partners like yourself, who can share information with African Americans about programs that you have so that we increase knowledge, education and awareness around all of the resources that may be available to either prevent cancer or, if you happen to be diagnosed with cancer, how the overall community can support people as they're along this journey.

Elissa: Are you utilizing at all volunteer community lay health workers? We did a podcast about a year ago where we talked to Dr. Steven Thomas, and he was working with barber shops. And so barber shop owners were able to do that outreach to the community and it seems like something that would be able to be done during the pandemic because people are still going to get their haircut now. Particularly as some restrictions have been eased a bit and it's a little easier and safer to go into barber shops.

So what are your thoughts on that type of program?

Dr. McNeil: So that is an evidence-based model for interacting with communities within their own setting, right. So instead of these healthcare workers or people from the healthcare that are not from that community, you identify trusted members of one's own community and partner with them to disseminate health information.

So from my early training in North Carolina, we developed lay health advisor programs in churches and trained church members to provide physical activity, colorectal cancer screening information, how to increase fruit and vegetable consumption within faith-based communities.

And then here in Texas, a lay health worker will be called a *promotora* and those individuals likely are licensed in order to have received training to be able to provide health education to the communities in which they serve.

So those evidence-based models exist for that type of engagement and more of us should be utilizing and working with those folks in order to have greater penetration within the community.

And within my faith-based organizations that I work with, don't necessarily label them lay health advisors, but it's a similar process that through that partnership, we identify someone who is at the church, who is the main person who wants to help disseminate that information throughout the church body.

Elissa: That's great. Now with all this community outreach, it seems that one thing you try to do is encourage patients to advocate for themselves. Now what is some advice that you could give to patients and caregivers listening today about how to advocate for their care?

Dr. McNeil: That's a good question. I'm thinking about it from this perspective that, of course, people probably are aware of and know the need to develop a relationship with a healthcare provider, ask questions from your healthcare provider about things that you're confused about so that you have the right education and knowledge that's needed to make healthcare decisions for yourself and for your family. And then we, of course, always tell patients to speak up when you feel that things aren't going in a particular way in which make you feel comfortable.

But what I feel what's underlying all of this need for advocacy is that there is often a feeling of lack of trust. And when you don't sort of trust the medical provider, you don't trust the staff, you don't trust the system, you know, that trust can lead you to do two things. It can lead you to withdraw and not engage, and then for others that lack of trust can lead you to see everything through the lens of mistreatment, right. You perceive every action as discriminatory; you perceive everything that someone is

doing, that they don't have your best interest in mind when, in fact, that may not be the case at all. And so, figuring out and identifying ways to build trust, I think, is a really key component.

Now the healthcare system and our providers need to be doing that. They need to do their part to instill trust within their patient, they are seen as authentic, they are seen as credible. They are seen as they have your back, they're on your side. Our job is to create an environment where patients can have a good experience that's based in trust.

But on the patient side as well we need to be trying to figure out, what do we need to know, what do we need to do that we can trust this provider so that when we see things and experience things, that it's not necessarily because someone is discriminating, it could be the implicit bias that's existing, and that we're going to talk and work with our healthcare teams to point out these instances where maybe there's more communication that needs to take place, maybe something wasn't done in a right way.

So I guess I'm looking at that question more from a trust building process on both sides in terms of like say the patient and the provider that says, "Yes, of course, do those things to advocate for yourself," but, really, work towards identifying a healthcare team that you can trust because, when you do, whatever recommendation they make, you're more likely to take it. When you do, whatever it is that treatment option, that clinical trial suggestion, you're going to hear them out because you believe on the basis that they are looking out for you.

So then the question would be, how can patients help sort of develop trust within their healthcare providers. And that's when I do think it is trying to spend time with them, trying to ask them some questions, trying to learn a little bit about their approach to medicine, that you kind of feel that this is the right healthcare team for you. Because when you feel like you have the right healthcare team, you'll follow whatever kind of

recommendation and advice that they have because they are the experts right in that case, and you want to trust the advice that they're giving you is what your family should do.

Lizette: Right, and you feel more open to speak to them about what your preference is because we always talk about shared decision making with our patients and, like you were saying, Dr. McNeil, it's really having that ability to communicate back and forth. And I think you're right, when you're not comfortable, you're not ready to communicate back and forth with your treatment team.

Dr. McNeil: Yeah. Relationships, particularly in a cancer diagnosis, is really, really critical. This is not a relationship where you just see him once a year for your annual checkup, so you may argue whether or not I have a really good relationship with that person is not that important.

Trust is critical here because people are going to be offering suggestions or treatment suggestions that really are may be the difference between life and death for a patient that's experiencing that cancer diagnosis.

Erika: Dr. McNeil, I would like to follow up with that question, you mention trust, which is a really big word and I believe that with my department in patient and community outreach, outreach is the core of our department, reaching newly diagnosed patients, patients that are in the middle of treatment, getting ready for a stem cell transplant. We want to make sure that they have the resources and our trusted support they need.

What advice would you give the next generation of community health educators and outreach managers like myself with connecting with local underserved communities?

Dr. McNeil: So I get asked this question a lot. I work in populations of color mostly. And the folks that want to help reduce disparities, want to do community engagement, really care deeply about the community often happen to be white Americans who look

different than the patients in the populations in which they're trying to serve. And so that question gets asked a lot, what can I do let's say as a white woman as I'm trying to build relationships, in Hispanic communities, for example?

And I say the same thing all the time because it's so basic but, it feels nebulous but it's not, it's actually pretty basic. And what it is, is we show up every day being authentic. That is what we do. We show up every day with a sincere heart, sincere goals and interests in mind. A mind of wanting to learn, being curious about the communities in which we want to serve, and to listen to their needs and hear them out.

And once you do that, you build trust within those communities and those populations, and you are going to be always challenged along the way, but you can navigate those challenges together because they trust you as someone who has their best interest at heart, that you kind of deliver for them. I'm not a miracle worker, I don't always get everything done. Everyone's not always happy with whatever it is that I'm saying or doing, but they know that I'm trying the best I possibly can on their behalf in order to work out whatever situation that might be. Many times, I'm successful, sometimes that I'm not. But even when I'm not, it doesn't negatively impact that relationship or their ability to hear me out, or their ability to want to work with me,

So even though I am African American, for example, and I partner with African American churches, when I show up, I recognize that, let's say when I first started my work here in Texas, okay, I'm from New York so I really know nothing about Texas culture.

Dr. McNeil: And so I had to be mindful that even though we look alike, that that was a difference, right, that I wanted to be aware of.

Then I'm what's called a "Preacher's kid." My mom is a pastor, I grew up in church my whole life. And so from a faith-based perspective, spirituality perspective or religion, we were similar, but I don't know that church, I don't know the people there, I don't know the history there. And so I approach every situation like that I might look like

you, but I don't exactly know you. And so I'm not too familiar. I take my time, learn people and listen. And then overtime desire to be as much of that community as I possibly can be.

So that's my advice for people who are coming and doing the work. You hear people, their situation, their life experience; sometimes very heartbreaking. You always want to figure out how to help people navigate the system and have better health outcomes. And we do that by showing up as our authentic selves every day.

Elissa: That's really great advice, thank you. Now, Dr. McNeil, on our patient podcast home page we have a quote that says, "After diagnosis comes hope." In your outreach to your local community, you have provided hope to patients and caregivers by way of education, caring, empathy and trust. Where do we go from here? What is needed to move forward to improve equitable access and care in cancer for underserved communities?

Dr. McNeil: So right now we have a healthcare system that's not equitable. It's just not. Whether or not you get to go to the number one cancer center for treatment is highly dependent on whether or not you have insurance and what kind of insurance you have. And if you don't have that right kind of insurance, then you're not going to be able to be seen there.

And this is why this matters and it's so important because research has shown is that when diagnosed with cancer, being seen, let's say for example, in a comprehensive cancer center setting, you'll receive better outcomes than some of those settings that are not as evidence-based, for example. And so when you get diagnosed with cancer, where you go it matters, but not everybody has access to it.

So, of course, where we go is changing national policies about how we treat people when they are sick, and how access to those lifesaving treatments are doled out within our society. I mean that really is just the beginning of that answer is that we need to change our healthcare system and make it more equitable.

And then that's why the Affordable Care Act, and other things like that, were really life saving for people because if you switched your job, that meant you may have lost your healthcare coverage and, therefore, not have been able to continue your cancer treatment or care. And so there are some shift in policies nationally that are trying to rectify some of those things, but that's one of the places that we'll need to go.

And then we also need better policies around how people get access to clinical trials. So, again, those clinical trials are going to be in those cancer centers, right. There are less opportunities in a community-based setting, right, at the local hospital, where you might be being seen in order to access those potentially lifesaving treatments for some people.

And so getting in the door, and then when you get into the door, how you get put on a trial is critically important. That right now it's not systematic in many of these settings, it is dependent upon someone to make a patient aware of a trial, and then invite them to participate. We have a lot more work to do to reduce structural barriers to clinical trial participation.

And what that means is making sure that every patient is being asked, making sure that every patient is run through the system so that they can see trials that match with their particular disease and condition. Making sure that we have what we call clinical trial patient navigators, for example, like lay health workers, that will meet the patient where they are and be able to talk through and support them through the decision about whether or not they want to participate in a trial, for example.

I want to focus on the structural barriers for accessing great healthcare and accessing clinical trials and not so much focus on the individual patient and what they need to do. You create a system that provides access, you create a system that reduces barriers, people will participate.

Elissa: Absolutely! Well thank you so much, Dr. McNeil, and Erika for coming on the podcast with us today. I think this was such a great discussion and good starting point



for people to hear about racial health disparities and how that is affecting so many members of our underserved communities and what we can do about it. And I know LLS has our public policy but, also, our Clinical Trial Support Center (CTSC) that can help people find clinical trials. So we're trying to do our part in it. We really appreciate you reaching out to the community and collecting all that data, and really trying to move this forward into an equitable space.

So, thank you again so much for joining us on the podcast today. We really appreciate it.

Dr. McNeil: Thanks so much for having me.

Elissa: And thank you to everyone listening today. The *Bloodline* with LLS is one part of the mission of the Leukemia and Lymphoma Society to improve the quality of lives of patients and their families.

To help us continue to provide the engaging content for all people affected by cancer, we would like to ask you to complete a brief survey that can be found in the show notes or at TheBloodline.org. This is your opportunity to provide feedback and suggested topics that will help so many people.

We would also like to know about you and how we can serve you better. The survey is complete anonymous and no identifying information will be taken.

We hope this podcast helped you today. Stay tuned for more information on the resources that LLS has for you or your loved ones who have been affected by cancer.

Have you or a loved one been affected by a blood cancer? LLS has many resources available to you: financial support, peer-to-peer connection, nutritional support, and more. We encourage patients and caregivers to contact our Information Specialists at 1-800-955-4572 or go to LLS.org/PatientSupport.



You can also find information about our community outreach through Myeloma Link at [LLS.org/MyelomaLink](https://lls.org/MyelomaLink). All of these links will be found in the show notes or at TheBloodline.org.

Thank you again for listening. Be sure to subscribe to the *Bloodline* so you don't miss an episode. We look forward to having you join us next time.