

LAZAREX PODCAST TRANSCRIPT

Luther Clark:

Hello everyone. This is Dr. Luther Clark, and I am the deputy chief patient officer at Merck. I'm joined today by Dana Dornsife and Marya Shegog. Dana is the founder and CEO of the Lazarex Cancer Foundation. Marya serves as the health equity and diversity coordinator at the Lazarex Cancer Foundation.

As a company, we are deeply committed to social justice and creating a healthier future for everyone. Dana and Marya, thank you for joining us today to discuss some of the barriers preventing equity in cancer clinical trials, and the importance of addressing current under-representation among communities of color.

How does the absence of diversity in clinical trials affect outcomes and survival rates in cancer clinical trials?

Dana Dornsife:

Diversity in clinical trials is essential in order to assess the safety and efficacy of drugs for all segments of our population, so that we are developing effective drugs and treatments for all segments of our population. Equal opportunity drug development, if you will. And you know, if we can achieve that, then that should lead to better cancer outcomes for everyone.

Luther Clark:

So what role does structural racism play and how does that show up in our work?

Marya Shegog:

Well one, in access, just the basics, let's go with the basics of the environment. Where health care centers are built. And then that the level of care provided. We see that in low-income neighborhoods, they don't have the same resources and health care facilities, as you would see close to a university or in a high-income area. And that's part of the physical structure.

There's also the structure within the health care system, where there is a decision made by the medical provider on who and what they're going to provide what information to, and as well as what options are available based on their health insurance coverage and in health insurance coverage and resources that they have to put towards receiving care and accessing care.

Luther Clark:

So, let's talk about some of the historic barriers that have led to under-representation of black and Hispanic patients in cancer clinical trials. How do these barriers impact the current state of clinical trials?

Dana Dornsife:

Well, medical abuses that have taken place over the course of history like Tuskegee and Henrietta Lacks, which are the two most common that people remember, but also cultural beliefs and customs, language barriers, challenges around socioeconomic status or the social determinants of health. All of these barriers have led to an ingrained lack of trust and fear about clinical trials.

And we have to adequately address this mistrust and fear before we can expect to see big improvements in clinical trial diversity. So, what does that look like? That means meeting people where they are, right? So they want to be engaged in the process and also have a voice in their health future.

Luther Clark:

So when we think about community partnerships, they've helped to raise awareness and combat distress among underrepresented populations. Let's talk about the impact you've seen in communities stemming from partnerships.

Marya Shegog:

So, I think one of the biggest things is that we have seen a willingness to talk about it. One of the things that cancer holds and still holds is a stigma. So, when we have been working with the community in Philadelphia, we seen that there has been an open up and willing to talk about it.

So, getting people to first talk about it, and then being willing to have conversations with people who actively conduct research, as well as provide care to those who have cancer begins to build a system of trust.

Luther Clark:

How can organizations within the cancer community work together to remove financial barriers and improve access to clinical trial participation for underserved populations?

Dana Dornsife:

So removing financial barriers for clinical trial participation is really one of the sweet spots of Lazarex Cancer Foundation. But we can't do it alone. We provide resources for cancer patients to reimburse their out-of-pocket travel expense, so they can literally get where they need to be when they need to be there to take advantage of medical breakthroughs in cancer clinical trials. But if they don't know about those trials, then it doesn't really matter, right? So we have to work with the medical community and the academic research community, right? To help them embrace and engage with these community members so that they understand what are clinical trials and what should I expect, right? Because that's really what this is all about.

Luther Clark:

So how do we overcome the biases of clinical trial design to ensure communities of color are more accurately represented?

Marya Shegog:

Oftentimes clinical trials or organizations that are doing the clinical trials have their specific cache of clinicians and institutions where they're going to get their patients referred to them from, and that is a convenient sample. So it means opening up and being purposeful and setting standards or setting percentages that you want to see and sticking to them instead of taking what you get or what comes easily or more easily.

Dana Dornsife:

Luther, before we move off this topic, I would like to just also add that this is a heavy lift. If this was easy, the work would be done, right? So it really is going to take a collaboration of all of the stakeholders to get the work done.

Luther Clark:

So, what would you say to someone who's a part of one of the communities historically underrepresented in clinical trials and is considering taking part, but maybe hesitant for any of the reasons that we've already discussed?

Marya Shegog:

A lot of times what you find is that people are scared because of past injustices they've experienced at the hands of medical providers. So kind of easing their fear and/or making sure they have a really well-informed health partner.

And if I could offer you one more analogy of that, the other thing that I always say is that many people like to believe that they're making changes in the world. So as these drugs are coming to market, I tell them, "Why do you want to wear the underwear of a white man?" If I'm talking to a woman, a black woman. It was like, "No, you have more booty than that. So you need underwear that fits you. The drugs work the same way. So, if we only have these drugs tested in the majority population and male, then we're not going to know how they fit you, and then you're going to get them on and you want to be uncomfortable for a lifetime? So no, go try them on and show them where they need to be fix and fitted and give you pockets so you can get a nice badonadonk," is what I tell my friends.

Luther Clark:

Great. So now we know that it's critical to remove barriers and increase participation among communities of color in cancer clinical trials. What impact have you seen in your day-to-day work?

Dana Dornsife:

Wow, that is a loaded question. Every day we observe new challenges and new issues that we need to unravel and address and reconstruct solutions for. So our day-to-day work now is really focused on yes, let's continue to provide clinical trial navigation and let's continue to get patients where they need to be and help them overcome the financial barriers, but let's have a continuous presence that is culturally appropriate in the communities that have the greatest health risk and help them navigate their journey from start to finish.

Marya Shegog:

Certainly Lazarex can make it easier for some who are looking for clinical trials with cancer, but it is, overall it is still easier, and they've created actual people, trial navigators that have this programs that people can go through that then they can have a job or a position to help people identify trials that they could fit into.

Dana Dornsife:

Also there's the advent of what's occurred as a reaction to COVID-19 and trying to maintain clinical research programs in relation to decentralizing trials and placing or creating less burden on patients to

participate in clinical trials. So rather than having them travel a long distance to the clinical trial site for simple things like a medical checkup or diagnostics to allow them to use telemedicine or the telephone to just check in, find out how they're doing, have their labs done locally.

Marya Shegog:

And there'll also be the opportunity to, I'm sorry, I just have to, there'll also be the opportunity I think, to reapply wearable technologies, which will then help reduce the travel and the burden. I know like with diabetes, people, they have, their blood sugar monitors are internet enabled and the doctor can monitor it and look at it from afar. Those same things can be reapplied and for cancer trials in the future.

Luther Clark:

So, we're coming to the end of what I think is really been a most informative and inspiring discussion. at Merck, we've been working very hard to achieve greater diversity in our clinical trials. And we've been doing that through a careful selection of trial sites, partnerships with community-based organizations within the trial site areas, outreach and education within diverse communities, in a dashboard that really allows us to track both our engagement and our enrollment success.

So with that, Dana and Marya, I would really like to thank you both for sharing all the excellent work that you both have done over many years in your careers, but particularly the work that you're doing at the Lazarex Cancer Foundation, and I look forward to having further discussions with you on a future podcast.