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Addressing Health Disparities for Black/African American Patients with Multiple Myeloma, Topic 2: Patient Journey & Education/Support

### Announcer:

You're listening to *Project Oncology* on ReachMD. This episode is sponsored by Amgen Oncology. On today's program, we will take you to a special Grand Rounds Educational Program, featuring an expert panel addressing health disparities for African American patients with multiple myeloma. In this episode, the panel focuses on the patient journey and support resources for patients enrolling in clinical trials. Moderating the discussion is Dr. Ian McFadden, Medical Director of Oncology Medical Affairs at Amgen.

### Dr. McFadden:

Alright. Thank you everyone for joining today. I'm Ian McFadden and it's my privilege to introduce our panel. Firstly, I'd like to introduce Mrs. Lenora Johnson. She's been married 54 years. She has two sons and four grandchildren. She dedicated an entire career to education, working for the Mississippi Institutions of Higher Learning, supporting the eight public universities of Mississippi and recently retired. Last year, Lenora was diagnosed with multiple myeloma. Presently, she travels 250 miles each way, three weeks out of every month to obtain her care as part of a clinical trial. Thank you and welcome Lenora.

Next it's my privilege to introduce Kimberly Bochel. Kimberly is a registered nurse with over 20 years experience in oncology nursing. She spent the last two years of that in the Blood and Marrow Transplantation Center at the University of Alabama at Birmingham, or UAB, where she is also clinical research coordinator. She's highly experienced with chemotherapy infusions, having formally been an Infusion Center Director. Thank you Kimberly, and welcome.

And thirdly for our panel, we have Dr. Luciano Costa who's an Associate Professor of Medicine at UAB, an active physician, and clinical trial investigator. Among the many employments, Dr. Costa is the Medical Director of the Cancer Center Clinical Trials office at UAB. Thanks very much for being with us, Dr. Costa.

So, I'd like to start with you, Lenora. You mentioned that you did take up a clinical trial at UAB. I'd like you to think back to before you did that, though. You know, what were some of your concerns and what were some of your challenges in even getting connected with that clinical trial?

### Lenora:

Really, the, the physician at the family medical group was really, kind of, my guiding force. I think his influence and his encouragement to me that that was probably the best if I could get in one. For me, it's always good to have someone around who knows and you being able and you being willing to accept, you know, their encouragement or their recommendations. But then I thought about this traveling and all of that, he was encouraging me to try and so I didn't think too much about it.

### Dr. McFadden:

I think you mentioned to me that you had to look further away because there wasn't anything as capable near you?

### Lenora:

Well, there was not a clinical trial in Jackson. In fact, I asked when I was going to the doctor for my anemia. I asked him, I said, why don't you all apply for some clinical trials? Y'all only have seven out here! So he said, well, you know, that they do apply, but I don't know what reasons that they don't get it. But they do apply.

### Dr. McFadden:

Yeah, I think that's, that's a critically important insight is some of these more community institutions may be interested in participating in trials but may not have the same means to do so and may not be selected as trial sites, even though, you know, clearly that's where a

lot of patients are being treated. Do you think that's typical, or is that, is that something that maybe might prevent someone else in your situation from being in the best possible hands?

**Lenora:**

It sounds typical because most people just say, okay, the doctor tell you what you have and you wanna know what the treatment is. And at that point you just wanna get some help. You're not thinking long-term that, because I know that my time I have more time in than out, here on this earth and I'd like to help somebody. So, clinical trials will help those coming along. And always you're, you're hoping that it helps you, but you, it can help those that's coming on. Because people ask me today, you go all the way to Alabama for your treatments? And I say, yes, I'm in a clinical trial and most of them don't know, don't have a clue about clinical trials.

**Dr. McFadden:**

Mmmhmm.

**Lenora:**

And so, to them, it's just not important. To them is that, you know, you just get treated, go somewhere to get treated and, and that's basically the difference, yes.

**Dr. McFadden:**

I think that's an incredibly well-said and I do wanna turn this to Kimberly quickly. What are some of the things that you do in particular in your role as a nurse to ensure, you know, equal quality of care and access to treatment for all of your patients? And even just getting a patient into the care facility. You know, I wonder if you could expand a little on that.

**Kimberly:**

Yeah, yeah, I mean myself, coming from a small area, you come to a large campus and if you're not used to coming to a campus as large as UAB, it's a little frightening. So you get this appointment, you're not really sure where you're going, where to park, who you're gonna talk to. And I, most of the time, Dr. Costa will see the patient and I'm the second connection they have here. So, I get with the patient, reassure them I have done maps of the campus for parking, I have literally met patients in our parking deck, walked them to a clinic, I have found they drive like Mrs. Lenora, hours and hours to get here, so they'll spend the night. So, you know, you get information and packets together, you get with the resources of social workers and patient navigators. It's coordinating, just getting them in the deck and getting them to the right floor. And it's just a fear of the unknown, so it's just helping guide them through that and giving them reassurance that it's going to be okay.

**Dr. McFadden:**

Lenora, I wanted to ask you, you know, do these personal touches and the care that you received from Dr. Costa and Kimberly, you know, is that, does that make a big difference in terms of you deciding to stay at UAB and stay on this trial?

**Lenora:**

Yes, and it did. Because I was new to the UAB system, I was new to the cancer, and of course, I was new to the research study. And so with Kimberly, I call her the patient advocate, but she's a nurse coordinator, but with her being there, she would always tell me what steps and what was coming and I felt comfortable in picking up the phone and calling her. I knew what days to call and, that she was genuinely interested in what we needed and not only me, but I could see her walking through the infusion clinic there and if we were not in the back, she would always come and sit with us and talk to us. But then if she found us in the infusion part, she was always there to answer any questions that we had or that we would ask or would just absolutely say, you know, well what can I do? What's goin' on today? And everything. And this helps the patients to really feel comfortable in knowing that these people really care and they don't mind you asking them questions, and that's important to me.

**Dr. McFadden:**

Absolutely. Thank you for that. You know, Dr. Costa, I wonder if you could speak a little bit to both specifically UAB but of also beyond just in general in your perception, what are some of the policies and what are some of the institutional changes that can make a difference here?

**Dr. Costa:**

You know, UAB has, many large cancer centers do have, you know, initiatives to engage with the community. We have a very active community advisory board that essentially helps guide bigger, and more strategic decisions, at the cancer center level. And I think that's very important. I think, we need to be intentional on our, recruitment and retention of minority faculty and employees. I think the more that the workforce medical infrastructure reflects the population that you're serving, the less cultural differences are gonna be become a barrier on a patient's success. Here we have a great experience with central Alabama's myeloma support group. It's a group that is about 80%, black patients and their families. It really goes a long way of getting patients educated and get patients to participate into

clinical trials because that's, that's very often on top of discussion.

**Dr. McFadden:**

Beyond patient education, I think a big component that you started to touch on is also investigator and faculty education. I'm wondering if you could speak a little bit about what you think works and doesn't work in terms of training culturally confident research staff.

**Dr. Costa:**

Yes, so that part is challenging, right? I think, Kimberly and I were talking about this the other day. Our society is very culturally diverse, but when you look at the medical community investigators, it's even more diverse. I mean, a lot of us, myself included are foreigners, our myeloma program three-quarters are foreigners. We have Asians, myself south American, have one investigator from the U.S. Many of us have been here in this country for many years but it's still you have a different upbringing that are different challenges in communication, or differences in communication that cannot be erased and should not be erased. It's part of how you are. How you take this very diverse group of people with some very cultural diverse backgrounds and help them have a connection, a cultural connection, a professional connection that does not compromise one's care and one's trust that is so necessary for clinical trial participation? And my experience is what you tell the patient and how much the patient trusts you. So those, that, the cultural recognizance, if you will, that empathy and building that trust, I wish we could erase one's biases. We can't, but we can learn to recognize and make sure that our communication with patients is one that is transparent, is authentic, but is also trustworthy.

Kimberly told me the other day, I know we all heard about all the jobs that she does that are extra nursing, but the other day I became more aware: this is also my, and so in a way, a cultural interpreter. One of the great features that Kimberly brings is that she grew up around here, the American south version of a diverse society, and so she understands. And she can communicate, the concepts with, with patients black or white far better than I can and far better than I ever will. Those are things that you don't do consciously but goes a long way into facilitating patient access to trials.

**Dr. McFadden:**

I think that's an excellent point. I want to come back to Lenora, actually, but just to boil it all down, what can be done now to better improve African American patients' journeys with multiple myeloma and their experiences? What can we do better for patients now?

**Lenora:**

Okay. When I was diagnosed and I began to talk to people about it, there were very few people who wanted to admit that they had multiple myeloma. And after talking to people I said, oh, you know, I didn't know that these many people had it. I don't know a support group around here, so I can't really address that as to how much support it would be, but I can just imagine that it would be. And I think Dr. Costa talked about the one they had in Alabama, where you can talk to people and understand what they are going through, or what they have gone through and even today, where you can give information. Information is so critical, and they can tell you about their experiences and you can tell them about theirs, and information that they know about that is going on. So, I believe in the support groups. I think that just being there, number one, and letting them know that you care and putting out, programs or information that would include and reach out to some of the other entities, like clinics, that work in these different communities with these people. And they know, from the ground up what is going on. And if you reach out to those kinds of clinics as well as the teaching institutions, then that can bring more information. Don't be tunnel visioned with it, but have a wide exposure of it that all African American communities could be included. So, you know where that is and you can always target those areas to be sure that accessibility is there, and the information is there.

**Dr. McFadden:**

Thank you for that. I think you're making a critically important point about bringing the access and bringing the resources to the patient-

**Lenora:**

Right.

**Dr. McFadden:**

-as opposed to the other way around. Thank you very much for that. And, and thank you again to all of our panelists. These are critically important insights for all of us as we try to strive to do better to support all patients and in particular African American patients with multiple myeloma.

**Announcer:**

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