

## THE BLOODLINE WITH LLS

A PODCAST FOR PATIENTS AND CAREGIVERS

### ***Episode: 'Community Outreach in The Field: Red, Bred & Led Houston'***

#### **Description:**

Please join us for the latest episode of our Community Outreach in The Field series, where our field correspondents, comprised of LLS Staff, will be on the ground interviewing health advocates, patients, caregivers and healthcare professionals in the communities in which they serve. These episodes will make listeners feel like they are right in the middle of the action!

In this episode, Mia Johnson, the National Community Outreach Manager for LLS's Myeloma Link program, hosted an event curated for Black women called "Red, Bred & Led" in Houston, TX. This weekend-long event consisted of a Sip and Paint Party, a Luxe brunch, and Sunday worship, all with an educational overview of multiple myeloma. This event heightened awareness of how myeloma disproportionately affects Black communities. A heavy focus was given on female caregivers, and how they can spread awareness and share resources available to them within their families and communities if a loved one is diagnosed with a blood cancer.

#### **Transcript:**

**Elissa:** Welcome to the *Bloodline with LLS*. My name is Elissa and I'm excited to introduce the next episode in our series "Community Outreach in the Field."

In these episodes, our field correspondents, who are made up of LLS staff around the country, will be on the ground interviewing health advocates, patients, caregivers, and health professionals in the community settings in which they serve. In this episode, Mia Johnson, the National Community Outreach Manager for LLS *Myeloma Link*, will be leading an event called "Red, Bred & Led," which is a weekend curated for Black women and those who love them.

Welcome, Mia.



**Mia Johnson:** Hi, thank you for having me.

**Elissa:** Before we send you out into the field, let's talk a little bit about what you'll be doing today. First, would you share with our listeners what the Myeloma Link Program is and why we have it?

**Mia:** Yes, sure. So Myeloma Link is a program that's carried out by LLS staff and volunteers in 16 Black communities across the country. It's an education and outreach initiative that directly connects Black patients and caregivers to trusted free myeloma information and support, as well as enhances the access to care and latest treatments. Our goal is to empower Black myeloma patients, caregivers, survivors, and families by increasing their access to the education and treatments for this disease.

**Elissa:** Wow, that's great. Now the outreach setting you'll be visiting today is an event called "Red, Bred, & Led." Could you tell us about it?

**Mia:** Yes. Red, Bred & Led is a weekend curated for Black women and those who love us. Red, because we're focusing on blood cancer, Bred, because we're born and bred Black, and because myeloma is bred within our blood. And then Led because we are then empowered to be our sister's keeper in the community by ensuring that we disseminate the knowledge about the available resources into the community.

**Elissa:** That's awesome. Now why is an event like this important?

**Mia:** So, the event is a weekend of education, collaboration and partnership and empowerment. In this we'll be merging what we love with what we need. Black women love paint parties.

**Elissa:** Yes.

**Mia:** We love Luxe brunches, and we absolutely love our faith. With that being said, the weekend of events will focus on elevating information about myeloma. along with resources and services that The Leukemia & Lymphoma Society offers to the Black



community through the Myeloma Link Program while doing things that Black women absolutely love and are vested in doing.

**Elissa:** So, how is the event going to go? What is each day?

**Mia:** It starts off Friday night with a Sip and Paint party with renowned artist Zina Martin. We're going to have a custom piece that is designed specifically for the event by Zina Martin. And she will do some trivia, we'll give out some prizes. Have great music, some light bites, and just really, really have a good time.

Then Saturday will consist of a Luxe brunch, which will have some music, some food, mocktails, personal stories, and then an educational overview of myeloma.

Sunday, we will end the weekend by worshiping with the Wheeler Avenue Baptist Church, which is a very popular church in the community known for its advocacy and outreach and its cancer ministries.

**Elissa:** Well that sounds so fun. So thank you so much, Mia, for sharing all about this exciting event. I'm really looking forward to hearing all about it, and we will catch up with you when you get back.

**Mia:** All right, thanks. I'm standing outside the venue where we will hold our first event of the weekend, a Sip & Paint party with renowned artist, Zina Martin. Looks like everyone is settled in and ready to paint. Let's go check it out.

Good evening, everybody, good evening. My name is Mia Johnson-Turner. I want to thank you all for coming tonight to our kickoff for the Red, Bred, & Led Weekend. Thank you so much. It is hosted, of course, by The Leukemia & Lymphoma Society; and just a little bit about it. So this is a weekend that has curated events for black wom-

As we got started, my LLS colleague, Erika Pomeroy, who is the Senior Patient and Community Outreach Manager in the Red River region of Texas took the mic to



introduce the paint artist, Zina Martin, and get us started with the Paint and Sip portion of the events.

**Erika Pomares:** I am Erika Pomares. I'm a Senior Manager of Patient Community Outreach with The Leukemia & Lymphoma Society. Welcome again. We really appreciate it.

We have Miss Zina here. She drove from Dallas, y'all, to be here, so we appreciate you. Thank you so much and to her daughter for accompanying her and helping out. We appreciate y'all.

Lika Mia said, we are here to celebrate you all and at the same time educate you all about blood cancers. Our goal is to raise awareness about myeloma but also about blood cancers in general. Part of Mia's and my role is to outreach to the Black community and making sure that they know about blood cancers and the resources and access to treatment.

Zina's going to do something really special tonight. She's going to incorporate teaching you all this beautiful stencil paint and then also trivia with blood cancer facts, and we have prizes.

**Mia:** Before the painting fun started, we introduced a special guest, Dr. Tracy Wilson, to share about her experiences as a caregiver for her husband with myeloma. She has an incredible story and a strong message for caregivers. Let's listen in.

Dr. Wilson is a caregiver to her husband, who is a myeloma survivor. We wanted her to come tonight to just share her story and to make sure that you all understand firsthand experience of the signs and symptoms.

**Tracy Wilson:** Good evening, everyone.

**Audience:** Good evening.

**Dr. Wilson:** I am excited to be here. I've been working with these lovely ladies for several months with this initiative. But to go back and walk with you all as far as with the journey with my husband. He played college football and basketball. And so, he had back pain. He went through physical therapy, had back surgery. We just thought that this back pain was just a part of the natural progression for him and his injuries of playing basketball.

We didn't think anything of it. But going back to 2017, he went to the Dominican Republic and came back with *Salmonella* poisoning. He was extremely ill. I had him go to the emergency room because he wasn't going. But had him go to the emergency room, and his white blood count was 0.

After about a week, we had his follow-up, and his blood count had not returned back to normal. Because of that, his primary care doctor said that I think we need to send you to hem/onc (hematology/oncology).

That started the trajectory of getting lab work done. That took probably about six months before we got the actual results because I think the due diligence of his hematologist/oncologist, he didn't want to give the diagnosis because my husband at the time was 39 years old.

Being that young, he was the youngest patient that they had with multiple myeloma. They wanted to be sure because they were trying to rule out whether it was smoldering (myeloma). And so he sent him to his mentor to actually do the additional testing before they did the diagnosis. I think it was December 28<sup>th</sup> of 2017 that we got the official diagnosis of multiple myeloma.

Being his wife, being a caregiver to walk the path with him, it was daunting for me because I knew a lot of the information; and so, to be in an office and to listen to the information of, "What do you want to do when you have to be put on the ventilator? What do you want to do if there is nothing else left to do?" When you're sitting in that kind of appointment, this is now my spouse, my life mate. And being on that side of it,



and I've been that caregiver to have to have the discussions with a patient; but now I'm the wife sitting in that appointment.

So, just wanted to talk to you all about that, thank you.

**Mia:** Thank you. And this is the reason why this is very, very important, particularly to me that we reach the women in the community. One of the things that we are learning is that the caregiver age is dropping quite a bit. I became the matriarch of my family at 38 years old. 38. I don't have a momma, I don't have a daddy, I don't have grandparents. I don't have aunties. I don't have any of that.

So, it starts with me. And as the caregiver in the Black community, I believe the numbers are like around 80% where we make the decisions on healthcare in the household. We lead the household when it comes to that. And so, as the caregiver, that means that this information is important to get to you so that you can have your talk with your man, dad, brothers, cousins, siblings, whatever the case may be because they're going to be relying on you to make those types of decisions. And like Dr. Tracy said, it's very different when you're sitting in that seat next to your loved one versus being in a professional role or watching it or hearing someone else talk about it. It's very different when you have to be the caregiver and you have to make those types of decisions.

So, please enjoy yourself, but please learn something as well. And now I'm going to turn it over to our artist for the night, renowned artist Zina Martin.

**Zina Martin:** Thank you.

**Mia:** And she is going to lead us with both trivia and a little bit of paint fun. And so, I'll just have you direct your attention to her.

**Zina:** Okay, thank you for that wonderful introduction. I'm just going to give you a little spiel about myself and about the trivia that we're going to do tonight.



So, again, my name is Zina Martin. My business is House of Zina. Kind of came up with that name

**Mia:** As our participants got started with their painting party, the energy in the room was growing. It was such an amazing group of Black women coming together for a common cause.

Later on, we took a painting break for some myeloma trivia led by our painting artist Zina.

For those listening to the podcast today, let's see how many answers you can get correct. Listen along with our onsite participants and shout out the answer.

Okay, so what we're going to be working on for our trivia, I'm going to be asking you questions about myeloma. Okay, if you know the answer, that's great. Go ahead and get your hand up so you can answer and win a prize. Is everybody ready to start?

All right, so what is the most common early symptom of myeloma? What is the most common early symptom of myeloma? First one who answers. Remember, this is also to educate you. Yes, ma'am.

**Speaker:** Bone pain.

**Zina:** Bone pain, very good. So, bone pain and/or fractures is the most common early symptom of myeloma.

Dr. Tracy actually said this when she gave us a bit of her story or testimony. Where is the most pain felt?

**Speaker:** Back, you can feel that.

The most pain is felt in the back or ribs, but it can occur in any bone. Okay.

Next question. When a person who may have myeloma, they may not be diagnosed yet, they may be feeling really tired and weak. What is that a symptom of? I've got two hands, like at the same time. It is fatigue. They'll feel tired and fatigue, but what is that usually an outline symptom of?

**Speaker:** Low blood.

**Zina:** It is low blood, anemia. So anemia is also a symptom. Very good.

Okay, what is another symptom, aside anemia, the fatigue, and bone pain? What is another major symptom that someone may be suffering? Yes?

**Speaker:** Frequent infection.

**Zina:** Frequent infections, very good. The immune system is often compromised, so they have multiple times where they're having illnesses. They get sick much more often than usual.

Myeloma patients may experience repeated infections because the body can't fight invading viruses, bacteria, or other diseases. Okay, let's see.

Who can give me, and there's several, so who can give a risk factor of myeloma? Yes?

**Speaker:** Race.

**Zina:** Race is one, very good. Okay, I got four more. Yes, ma'am?

**Speaker:** Age.

**Zina:** Age is another one. Excellent. Anyone else? I've got-

**Speaker:** Sex.

**Zina:** Sex, very good, mom. Anyone else? I've got two more.

**Speaker:** Family history.



**Zina:** Yes, family history, medical history. People with a history of MGUS [monoclonal gammopathy of undetermined significance], which is a condition in which an abnormal protein known as monoclonal protein or M-protein is in the blood. Race, Blacks are nearly twice as likely as whites to develop myeloma. Age, most people who develop myeloma are over 50 years old. Sex, more men than women develop myeloma. Okay, I've got one more risk factor. Who can tell me what that other risk factor is? One more. And I'll give you a hint. This is a risk factor that comes up in a lot of other conditions.

**Speaker:** Weight.

**Zina:** Weight, very good. Obesity. New research suggests that obese people have a higher rate of myeloma. Okay, that's it for now. I do have more trivia that we'll get to later.

**Mia:** After the painting and trivia, we caught up with the Artist Zina to hear what she thought of the event so far. We had tasked her with the trivia game, but I also wanted to know about her awareness of blood cancer prior to the event.

I'd like to introduce Zina Martin, the artist leading the Sip and Paint Party. First, thank you so much, Zina, for participating in this event today and helping us bring awareness to blood cancer. Why do you feel like an event like this is important in reaching Black women and their families?

**Zina:** We know that we as Black women love to pamper ourselves. We do like to take care of ourselves, and there's a growing trend of that in our community; but these types of events are wonderful to spread awareness and education. That's a part of their healthcare routine in making sure that they are checked out. You know what they say about trying to discover it early, treatments, and things like that; and so since it's such a big deal in the Black community, we really want to make sure we get the word out, and what better way to do it by also pampering them at the same time.



**Mia:** Absolutely. Prior to this event, were you aware that myeloma affected the Black community more than others? And after leading this painting and trivia about blood cancer, what have you taken away from this event?

**Zina:** So, I was not aware of that, actually. I was shocked to see the numbers and how disproportionate it is, of course, against other races; and we kind of see that issue with many things in the medical community and when it comes to the Black community.

After the event and learning more about it, of course, now I'm kind of hyped about getting myself checked out, doing what I can as far as healthcare, food intake, the liquids I drink. I've got two daughters. I definitely want to make sure that they are well aware and in the know. One actually attended tonight with me, so I'm, I'm excited that she got to learn more; and my mom and sister are here as well. And so, knowing that we have plenty of things in our family as far as illnesses and some connected to cancer, specifically ovarian and cystic cancers, cystic fibrosis, this was really important. So, I was really glad to take away some of the information we learned and to take it back to other family members as well and friends.

**Mia:** Thanks again, Zina. I appreciate it.

As we mentioned in the beginning, this is a two-day event, so we came back the following day for the Luxe brunch. We interviewed a couple of very important women in the Houston community. Take a listen.

We are back for Day 2 of Red, Bred, and Led. Today we'll be having our Luxe Brunch and sharing all about Myeloma Link and blood cancers. We've asked participants to wear red for blood cancer, and we are so excited to spend some time connecting and spreading awareness. Let's go ahead and go inside.

All right, I am here with President Junelle Berry, and she is with the National Coalition of 100 Black Women Incorporated, the Houston Metropolitan Chapter. First, I want to



thank you for your collaboration and putting on our event today for Red, Bred, & Led in efforts to bring more awareness to blood cancer in our community. So, tell me what you thought about the event today.

**Junelle Berry:** Today's event was wonderful. It was well-planned out. Learned a lot about blood cancer and the signs that we need to look for, both in women and in men. And that men tend to be the number one factor that are being affected by it.

**Mia:** Awesome why do you think this type of event is important to the Black community or particularly to women?

**Junelle:** It is a disease that is impacting us, and we don't really know much about blood cancer. We know that there's cancers of the bone, cancers of the breast, but blood cancers is something that we don't have a lot of information on, and we need that information so that we know that it's affecting us and the numbers that it's affecting us.

**Mia:** Is there anything that was particularly alarming that you learned today that you're going to be taking back to your community or to the community of the Coalition of 100 Black Women with the Houston Chapter.

**Junelle:** I think the thing that was particularly alarming for me is the effect that it had on the caregiver, and how it affects them as well as the person that is going through the treatment. We always think of only the person that's going through the cancer diagnosis, but we forget about the caregiver. So, listening to that part of it, I think we need to give a little bit more light to that for the caregivers.

**Mia:** Absolutely, I definitely agree with that. Well, thank you again. It has been wonderful collaborating with you. We look forward to doing some others in the future, and let's go back to the party.

**Speaker:** Thank you.



**Mia:** Our next special guest for this event had a very special surprise for us. On behalf of Houston Councilwoman Letitia Plummer, she presented the Red, Bred, and Led event with a Certificate of Appreciations to thank The Leukemia & Lymphoma Society for its commitment to improve the health of the Houston community. We were so excited to receive this amazing honor and wanted to hear what she thought of the event and how we could move forward within the Houston community.

Hello. I am here with Ms. Katherine Washington who represents Houston Councilwoman Letitia Plummer. And she'll be presenting a certificate on behalf of Councilmember Letitia Plummer and her office to present to us here at Red, Bred, & Led Luxe Brunch. Thank you so much for attending. What do you think of the event so far?

**Katherine Washington:** I think it was a great event. A wealth of knowledge that probably a lot of our Black relatives and just people in general don't even realize. We have a backache; we think it's just a backache. But it could be something else. The event was very nice and just a lot of knowledge.

**Mia:** Thank you, thank you. Let's talk a little bit more about something you actually just said in terms of why it's important. But very specifically, why do you think it's important to reach Black women in this field regarding blood cancer?

**Katherine:** Because we are probably the head of the household; and we are the ones that are mainly the caretakers.

**Mia:** Very important. And so are there any other thoughts in regards to your experience with us you'd like to share with the community?

**Katherine:** I would just like to take this nugget back to my office and share it and try to reach the community and just spread the word.



**Mia:** Right. Well, thank you so much again, and we appreciate you coming. Tell the councilwoman we appreciate her token and her certificate as well, and we look forward to doing more in the future with you.

**Katherine:** All right, thank you. It was my pleasure.

**Mia:** Thank you so much.

**Elissa:** We are back at the studio following the Red, Bred, and Led event. Thank you, Mia, for bringing our listeners to this event.

In the last episode, our field correspondent Brian Daily attended the *Blood and Chess* event in Atlanta which was also part of the Myeloma Link Program Outreach.

How do you feel these events will help with the continued outreach to spread awareness about myeloma and other blood cancers?

**Mia:** So Black Americans have at least double the incidence of myeloma as any other race or ethnicity and recent studies show they face an additional barrier and lower access to care. And one of the things that The Leukemia & Lymphoma Society is determined to do is erase these disparities.

As I mentioned earlier, the goal of Myeloma Link is to empower Black myeloma patients, caregivers, survivors and families by increasing their access to education on this disease, or even the treatments for this disease. And it's important because in the Black community, it is very common for the families to rely on one another for treatment or support. And, typically, there is not a lot of knowledge about what they can do to, bring some type of awareness, education, access to treatment, or even clinical trials within the family.

If we are able to continue to provide these types of awareness events in the community, not only will this bring the education to the patients, caregivers, survivors



and their families so that they're able to access this type of education and information on treatments. That means it's also going to affect the prognosis of the said diagnosis.

Why? Because we're getting people in sooner. We're able to treat the disease sooner and able to give them the access to the quality of the care that is necessary to address some of the barriers in health disparities.

**Elissa:** Thank you so much again, Mia, for being our latest field correspondent in our community outreach in the field series. *Myeloma Link* is such an important program to bring awareness of myeloma and other blood cancers right into the heart of communities of color.

As we mentioned earlier, outreach to underserved communities is a crucial step in addressing racial and ethnic healthcare disparities, and we really appreciate all of the work that you and your team have done.

**Mia:** Thank you.

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

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In addition to the Lounge, we could use your feedback 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](https://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 completely anonymous and no identifying information will be taken. However, if you would like to contact LLS staff, please email [TheBloodline@LLS.org](mailto:TheBloodline@LLS.org).

We hope this podcast helped you today. Stay tuned for more information on the resources that LLS has for you or your loved one 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](http://LLS.org/PatientSupport). You can find more information on the *Myeloma Link* program at [LLS.org/Myeloma Link](http://LLS.org/Myeloma Link). These links will be found in the show notes or at [TheBloodline.org](http://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.