

## THE BLOODLINE WITH LLS

A PODCAST FOR PATIENTS AND CAREGIVERS

### ***Episode: 'Bridging the Gaps: Striving for Accessible Cancer Care'***

#### **Description:**

In this episode, Dr. Sharon Castellino, a pediatric oncologist at Children's Healthcare of Atlanta, examines the impact of healthcare equity and barriers to care for patients and caregivers dealing with blood cancer.

Dr. Castellino sheds light on how groundbreaking treatments have transformed the landscape of cancer care, emphasizing the crucial role that LLS, patient advocates and government entities can play in ensuring accessible and quality care for all.

#### **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. Sharon Castellino, a Professor of Pediatrics at Emory School of Medicine and Director of The Leukemia & Lymphoma program at the Aflac Cancer and Blood Disorders Center in the Children's Healthcare of Atlanta. Her expertise is in the study of outcomes and late effects in patients with hematologic malignancies and in the design of clinical trials in pediatric oncology. Dr. Castellino's work across clinical trials, outcomes, and health services research has always included a focus on examining disparities in cancer outcomes by race, ethnicity, and age. Welcome, Dr. Castellino.

**Sharon Castellino, MD, MSc:** Hi, thank you. Thank you for the opportunity to speak with you all today.

**Elissa:** Thank you for being here with us.



Our episode today is on health equity. Could you tell our listeners what that is and why it's important in cancer care?

**Dr. Castellino:** So, I think about health equity as the concept that all treatment that we give, whether in cancer prevention, in cancer treatment, or in survivorship shows equal amounts of benefit to all populations. And those populations may be within an age group, across a racial and ethnic group, and in some other factors that we can get into. But it's really about if we're making improvements and strides that all patients are benefitting equally from our advances in medicine and specifically in cancer care.

**Lizette:** And in the cancer space, we talk a lot about underserved populations. So, what groups are these; and what makes them underserved?

**Dr. Castellino:** Yes, so it can start within pediatrics since I'm a pediatric oncologist. And within pediatric cancer, which are, increasingly more and more curable, that the underserved populations tend to be children who are from racial or ethnic minority groups within the US. That doesn't even start to address underserved populations in terms of our global health where patients and families are resourced even more differently than within the US.

Within the pediatric space, we can also describe differences in terms of underserved populations by age. Specifically, adolescents and young adults have a variety of reasons for which they have had more health inequity compared to their younger counterparts and their slightly older counterparts of adults with similar cancers.

In addition, I think we increasingly recognize that rural patients might be more underserved than patients living in larger metropolitan areas. And then, also importantly, children or adolescents who may be of nonbinary gender or have other gender minority classifications may also be at risk for not having the same access to care or the same quality of care or same outcomes with cancer treatment.



**Elissa:** Speaking of access to care, some patients may have difficulty accessing affordable and quality care. What are the factors that may affect access to care?

**Dr. Castellino:** Yes, so I think historically we've always thought about access with regard to things like insurance. And insurance, which is not universal and in our United States system, is one major entry in terms of access to care. But increasingly we realize that there are many, what I would call upstream factors from the patient themselves or from the family themselves in terms of access to care; and those have come under the term of social determinants of health.

Social determinants of health have been delineated by the WHO (World Health Organization) and by the Center for Medicaid Services (CMS) and by healthy people as being conditions in the environment where people are born, live, learn, work, play, worship, and age. Now that covers a whole host of developmental stages in life, social circumstances in life. But we realize that these can all affect wellness and health even before you're diagnosed with a disease, and then certainly more so when you're diagnosed with a chronic disease that has acute components to it like cancer.

Even if you have insurance, access may be impeded by transportation to the appropriate kind of healthcare center. For example, the kind of healthcare center that you might need specialized pediatric or adolescent medicine care in may not be within the vicinity of travel. In the Southeast, for example, where we have less access to public transport in most major cities and metropolitan areas, and not everybody has a car. Access is a different issue than maybe if you live within a city that has a better subway system. So, access can vary across these different groups that we have mentioned before for various number of reasons.

**Elissa:** I'm from a little bit more of a rural area and I remember when people would get diagnosed with a more serious cancer like a blood cancer where you'd need a specialist, you'd have to drive 3-1/2 to 4 hours; and I think that that made it inaccessible for so many people because you'd either need money or family support

and maybe leaving your job for a little bit, lack of income to be able to drive to the other side of the state to a major cancer center to get treatment.

So, I could see this as a real problem, whether you live in the city and don't have access to that public transport that may get you exactly where you need to go to the cancer center, or if you live quite a distance away from the major cancer center that has a specialist for you.

**Dr. Castellino:** Yes, and I think that over my career I've seen that some of that has been exacerbated by two things. One is that we have tried very hard in medicine to create treatment regimens for cancer and approaches that allow patients to be out of the hospital, to be home, to be outpatient. Paradoxically, that has caused more of a gap in access because, for example, we have some regimens where a child may have to come to the treatment five days in a row. And while that allows them to be home and be in the clinic for two hours a day for an infusion, in reality, that's not easier for many families.

It might have been easier when they were able to come on a Monday and then take the child home on a Friday because they have other children at home. They have to go to work. And so, I think we have realized now that it's because of distance. In pediatric cancer, it's because somebody has to work to maintain the insurance or just to pay the bills for the lights and the rent and pick up the other child from school who's not affected with cancer and who they're trying to normalize life at home.

So, I think that there are these kind of issues that are relevant to transportation but also patients being taken out of their community support, which is also very important for families during cancer treatment.

**Lizette:** You've already discussed some barriers in care for patients, and now you're discussing more disparities that affect cancer outcomes. What can patients, caregivers, healthcare professionals do to affect change and have better health outcomes?

**Dr. Castellino:** Yes, so I think that where we as healthcare professionals and scientists have really focused largely on the biology of cancer, on risk-stratifying therapies so that we try not to overtreat or undertreat patients in terms of the intensity of therapy they get. We have just huge growth and a surge in novel agents over the last 15 years that are really biologically targeted.

But I think as we continue to make advances in those areas, we realize that not everyone is benefiting from those advances. And so, what we have to do is to also include a mapping of the social determinants of health early on in our assessment of a patient with a new cancer diagnosis. It may be as important that a patient has a certain translocation as it is that they can't get to their therapy appointments, or they don't have insurance to pick up their oral daily chemotherapy which we know is effective if it is taken. But if we don't know that it's, can't be picked up, I mean sometimes we'll realize that from looking at the blood counts that a patient has not been taking their medicine and then can slowly unravel the fact that, if you call the pharmacy, they haven't picked up their medicine in two months. And then you realize that the family didn't realize that their insurance had lapsed and, therefore, they were confused as to why they couldn't pick up the medicine.

And so, I think that these are really granular things that need to be addressed at the start of therapy and repeatedly during therapy because the social determinants of health don't get resolved, and they may have an increasing role as the time goes on from therapy.

Oftentimes, I'll see that at initial diagnosis, there will be a large community with the family there because of the angst of a new diagnosis. There will be a pastor and grandparents and community members who come to support the family; but for the most common blood cancer in children, acute (lymphoblastic) leukemia, therapy goes on for three years. And then slowly I see that there's nobody, other than the single parent or the two parents trying their best to hand off and manage their kids, and



they're there by themselves. And so I think that we need to not just do that intake of needs at the beginning but reevaluate that periodically.

From the family side, I think they need to know that there are many programs, people who can assist with that; and we need for them to trust and know that they can ask for help because I do think maybe families are embarrassed or they don't realize that there are social workers for the pediatric programs. They help with everything from making sure patients get to appointments, making sure they get their medicines, making sure that the employer paperwork is done in an appropriate way so that the family takes advantage of their medical leave policies, etc., so that the family is supported.

So, I think that increasingly over my career as I've seen novel therapies advance, I've become more worried that those advances are actually gonna get a wider gap because the complexity of delivering care for the patient in outpatient setting in this country has become more and more onerous. And, it really does take a village; and that village has to include our policy, governance, at the highest national level, some harmonization across the country for insurance policy and care delivery so that young families and adolescents and young adults who are not necessarily going to stay in the place where they are initially diagnosed with treatment don't have to reinvent the wheel and figure out a new system in a new state.

We know some days we're like 50 countries, and I think, that's really true for the patient undergoing acute care for cancer. But then it comes up in the survivorship space as well. After they're done with therapy, they may have monitoring needs. They may have a relapse. They may have late effects from their cancer and so need continued care. But they're highly unlikely if they started care somewhere when they're 10 years old to be in that same place when they're 18 or even 25 years old.



**Lizette:** Yeah, so our cancer advocacy groups and nonprofit organizations and even the healthcare systems can provide more education to try to help with some of these gaps, right?

**Dr. Castellino:** Yes. I think that advocacy groups, like The Leukemia & Lymphoma Society, have great resources so that if maybe you're not in a place that has a huge battery of social workers, if you're more in a rural setting, families can be pointed and realize that they can find reliable resources from organizations like The Leukemia & Lymphoma Society.

LLS has also been great about developing age-specific and developmental-specific guides to how to navigate treatment. Those are resources that are really important for patients, whether or not they are at a large center.

So I think that the education, the increasing one's health literacy as a patient – I've looked after children and adolescents and young adults with cancer now for 30 years but have really learned the most about the pain points of our healthcare system and about living with a diagnosis of cancer from my experience with navigating my own sister who was diagnosed at age 23, a few years out of college, with cancer. But all of a sudden, we lived the issues of AYA cancer every day. And she's been 17 years in remission; but every year it's something new. It's cumulative, the financial toxicity that we read about and navigating the system.

She has doctors in her family, so I can call up on her behalf, and I can recognize things. She's taken over her own needs largely, but every now and then I have to call the pharmacy and say, "I don't know what's going on with the disconnect in your insurance verification, but she is completely insulin-dependent, so it cannot be two weeks until you send her insulin." I have the wherewithal to advocate for her, and she has the wherewithal to come to me.

Parents do a great job learning the ropes over time with their children. I see many parents after their child has gone through treatment, and then many young survivors



going into healthcare professions after they're done with their acute care because they really have learned how to navigate the language. But I think that we just need more coordination so it's not one off for every family.

**Elissa:** Yeah, it definitely seems like cancer patients are often left to find their way on their own and figure out how to navigate the system.

I was diagnosed in my 30s with leukemia, and so I definitely had to figure it out. And I finally was able to get connected with LLS and see the resources there and get connected with a bunch of other AYA cancer organizations, and that was so helpful. But I did feel like I was on my own to some degree; and I was also not one to really ask for help.

**Dr. Castellino:** Yeah.

**Elissa:** So, I was like, "I can do it. I can just figure it out for myself." I could figure out where to buy wigs and figure out how to do this and figure out insurance and all of this stuff. And, yeah, I do feel like you are sometimes kind of left on your own a bit.

**Dr. Castellino:** Yeah, I think that not all cancer programs which have gone by disease focus – breast, prostate, pancreatic have had the same kind of growth and force of the patient navigator system equally. And it's not clear to me why. The breast community has done a marvelous job in demonstrating the power of having a patient navigator.

I had another family who was an older adult with breast cancer, and I was just amazed at how that navigator stuck by her from start to finish. And then, when there was a scare of a recurrence at a different point, she was able to, years later, connect with that same person to take her through. And so, I think that the lack of navigation outside of the breast space is a big void.

And I think just the ins and outs of the financial management of cancer is a full-time job. Not to mention when you're a young adult and you're sick and you're also trying





to, negotiate your work hours and your workability, which, even if you are able to go to work, you may not be able to be present in every way.

And, even with the Affordable Care Act in many states, not all states have Medicaid expansion. There's still a lot with the hospital bills and just your own household expenses and things to keep afloat. And when people are ill and feel sick and where parents already are trying to work a job, be in the hospital for chemotherapy with their child, and then also manage the children at home, they need another point of contact.

So, the many services at The LLS, I think, are a great start for patients with blood cancer. But to me the optimal situation would be that from the day you're diagnosed with cancer, you have seamless insurance. That you don't have to renegotiate every six months, as many patients with Medicaid do in certain states, and that you have a navigator who is your continuous support throughout your acute treatment and through your survivorship. I think that would make a big difference and perpetuate the successes we've had in biologic approaches.

**Elissa:** Yeah. Now, these gaps in care, so difficulty accessing care, whether it's through transportation or insurance or anything like that, is that actually affecting the cancer outcomes, so the survivability of cancers?

**Dr. Castellino:** Yes, I think we have data that shows that. We have data showing that the gaps in care can affect adherence to recommended treatment or recommended follow-up care. Dr. Smita Bhatia showed some years ago that a drug, an antimetabolite drug called 6-MP, which is a mainstay for maintenance therapy in patients with acute lymphoblastic leukemia, that taking your medicine was, as measured in your blood that you're receiving the medicine, was directly associated with a risk of failing treatment if you weren't when having a relapse.

And so to go back to my prior example, there's so many reasons that patients don't get their drugs. It could be that they don't pick them up. It could be that insurance won't let anybody know that they can't be refilled for a variety of reasons. And maybe health



literacy issues that a parent who now sees a child who is no longer looking sick and returns to school or a young adult who knows that that chemotherapy doesn't make them feel great. But, they feel better overall and so there, it affects adherence; and so, I think that, those are many issues that these gaps in care can show.

We have recent data that my colleague, Dr. Xu Ji, Health Services researcher here at Emory, has shown in a national data set of childhood adolescent and young adult blood cancer survivors that discontinuity of insurance can lead to up to a 20% difference in outcomes and survival over five to seven years. You see amongst patients who are enrolled in Medicaid discontinuously, that there is a big difference in survival compared to private insurance holders who are more likely to be continuously enrolled. So, that's just one example.

Now, it's likely that there's a large intersection between the patients who, for whatever reason, whether it be socioeconomic, whether it be young age, whether it be lack of resources, intersection between those patients who of minority race and ethnicity and patients who live in rural areas. There's likely a big intersection between those groups. I think the discontinuous Medicaid is just one sort of surrogate marker so to speak for those other risks that the same population is experiencing.

So, we have multiple examples of diseases that we know are treatable and that we can put into remission and keep in remission. But the medicine has to be delivered and taken, and side effects have to be managed so that patients can continue to be effectively treated.

**Elissa:** Yeah. I'm glad that you mentioned data and that there is research in this space because you talked about it taking a village, right? So, we would need that data to show where the gaps are, what the problems are so that, hopefully, we can get public policy change, we can work with healthcare professionals, nonprofits to make sure that we are finding ways and finding solutions to close that gap, right?

**Dr. Castellino:** Yeah, there are many around the country who are looking at this from several levels. So, as you mentioned, we can start at the policy level. And policy, and not just insurance policy, which I've harped on a little bit and harmonizing that on a national level but local policies. There are ERs that may decline patients. There is evidence of systemic racism where, a mother will say, "I have been taking this child to the hospital for two weeks because I knew something was wrong." And no one ever even did so much as a complete blood count, which is very easy way to first show a disease like childhood leukemia.

And, so I think there are maybe local policies and awareness. We need providers who can face their own potential biases. We need more representation across the provider workforce of people who can then, create a trust relationship with our diverse population who are more at risk for not getting diagnosed in a timely fashion and they're then not complying with the recommended treatment because of all these various factors that are often beyond their control. And then after treatment, I think we need to sort of continue to have those approaches to keep people engaged in their survivorship care.

So, there's multilevel barriers and I think that they need to be measured. And we are now doing that. There are now going to be CMS (Center for Medicare & Medicaid Services) codes to put into your diagnosis problem list like housing insecurity, transportation security.

**Elissa:** Wow.

**Dr. Castellino:** And that's really new within the last couple of years.

So, I think that, on the policy level, there are those things happening. At the individual level, communities need to be engaged to make sure that if clinical trial is available, that it's offered to all patients, that we have representation because right now the majority of our data is based on non-Hispanic White populations. And so, we don't know if there are tumor microenvironment or other issues that may be affecting the

metabolism of a drug in a different population or the ability to tolerate a drug in a different population.

So, that's at the treatment level. It takes sort of community engagement for providers and advocates to make sure that there's representation in clinical trials. And then on the treatment level after treatment, there needs to be continued engagement for survivorship care.

**Elissa:** Now, speaking of research, are there any factors that may come into play with patients accessing or even knowing about clinical trials they may qualify for?

**Dr. Castellino:** Right, so the issue of clinical trials is, again, sometimes tricky because depending on where you present with your disease, where you decide to stay for treatment, there may or may not be a clinical trial available.

So, certainly groups like LLS have the ability for a patient to call and ask when to get more information on clinical trials. But again, that first step is a big leap. And in a lot of blood cancers, for example, treatment has to start pretty quickly. You don't even have sometimes 48 hours because patients may come in so ill. However, there's many kinds of clinical trials. There's clinical trials for treatment. There's clinical trials for supportive care, and there's clinical trials for determining the vast approaches to fertility preservation. So, there are many options for clinical trials.

We do know, again, that there is a gap in clinical trial enrollment by race and ethnicity where children and adults who are Black or Hispanic may be less likely to enroll in a clinical trial.

We know that adolescents and young adults, for a variety of reasons, have not enrolled in clinical trials; and we have been trying to address that by having trials that are more pragmatic and maybe more simple, less complicated to understand, less complicated to explain the risk to patients so that it's not as scary because, unfortunately, there's still a perception that clinical trials give experimental treatment

with that word being used in a negative connotation. Explaining to people that, yes, there are risks with new therapies, but there also could be benefits.

Clinical trials have advanced our ability to deliver curative therapy for patients. Now, there's a lot of focus on deescalating the more cytotoxic therapies and if we have novel agents that may have less side effect burden. But there's no way to know that until we get representation from patients on trials by race, by ethnicity differences and by age differences.

**Lizette:** What advice would you give to patients who may face healthcare disparities? Is it helpful when they participate in shared decision-making with their treatment team and advocate for their own care?

**Dr. Castellino:** Yes. I think that shared decision-making is really important, and the point I would like to make about that is it takes time. It takes provider time with a patient. Again, it's not something that happens at just one point in time. People need time to digest the information, to consult others if they're thinking about going on a clinical trial.

And shared decision-making, I think, importantly, involves a myriad of factors beyond just like, "Are you going to get treatment A or treatment B?" They need to understand what the tradeoffs may be between treatment A, treatment B, whether it's on a clinical trial or not. They need to understand what their obligations might be in terms of coming to clinic with treatment A or treatment B.

So, for example, with this treatment, you'd have to be back on days 1, 2, 3, and 8 of every 21-day cycle versus with another treatment you would only need to be here on day 1 and 15 of every 28-day cycles.

However, the latter regimen goes on for six cycles. The former regimen is five cycles. And here are the differences in what we know to be five-year disease-free survival with these two approaches.



In our diseases where we have really favorable outcomes now, upwards of 85% in diseases like Hodgkin lymphoma, those might be really relevant discussions. With some of the new agents, we also have to disclose that they have not been around long enough for us to understand whether there will be late effects, just like with conventional chemotherapy. We didn't really detect the issue of late effects until it was 15 to 20 years after the initial cure.

So, I think that sometimes those are hard discussions for a family who's overwhelmed with a diagnosis. And then, if it's an adolescent or a young adult, where does their autonomy need to be regarded with the context of their parental support? They need to think about things like school attendance and how much school will they miss. So, I think shared decision-making is really a bidirectional communication between a provider and the patient, and their family in many situations.

In addition, I want to remind people that shared decision-making isn't only just about the acute treatment as we just discussed. It's also about supportive care. It's also about do you want to wait to start treatment if you're safe to do that medically because you want to look at a fertility preservation option, and is that even feasible given your insurance and your resources and the family's values around that?

Shared decision-making also needs to include a discussion early on of survivorship. Like, we expect that you have an 85% chance of having this cancer go away and not coming back. But we also need to remind you now that you need to be followed over time. So that people don't just think that it's a one-time thing.

People are so overwhelmed with that first discussion. And so shared decision-making, you have to come back again and again because people only absorb, I think, about 10% of what you say in the first discussion of cancer, right? And then they come back.

**Elissa:** Our final question today, on our patient podcast home page, we have a quote that says, "After diagnosis comes hope." For patients and their loved ones listening



who may face barriers to care, what would you say to give them hope after a cancer diagnosis?

**Dr. Castellino:** I think we live in an incredible time, and it is so gratifying to see the advances that we've had in medicine, in blood cancers.

I just came back from the American Academy of Cancer Research (AACR) meetings, and the science is explosive and phenomenal. But we need to learn how to communicate it correctly to patients so that they embrace and trust the science. And we need to create this infrastructure support to help patients through because the drugs are there, the treatment regimens are effective, but they are not easy. And so, I think when I would say to people "there is hope" is that we can treat you, but we need for you to hang in there with us and help us to help you create the support around you and your family to get you through this treatment.

And so, we think that we have a huge armamentarium of therapies that are effective for blood cancers, and to me that is hope. And we just now, as a nation, need to embrace how to deliver that and preserve the rest of the quality of life for patients going through that.

Now, I think we're getting there. I think just even acknowledging this term "social determinants of health," which didn't exist in the '90s, just like tyrosine kinase inhibitors didn't exist. I think of them in the same realm that we need to think of these as treatment and risk variables that will continue to be measured; and then with measurement we can improve them, and that can improve the quality of health for all patients.

**Elissa:** Well, thank you so much, Dr. Castellino. I think this was an amazing discussion all about health equity, really understanding the gaps in care that a lot of our patients are facing right now and the disparities and also potential real-world solutions where we could get involved with public policy. LLS can find ways to make



sure patients are educated, and also addressing the gaps on our own. So, thank you so very much for coming and speaking with us today. We really appreciate you.

**Dr. Castellino:** You're welcome, and I really appreciate all that LLS does for the blood cancer community because it doesn't just help patients with blood cancer. But I think it's creating models for patients with all kinds of cancer and especially pediatric and young adult cancers.

**Elissa:** Absolutely, well, thank you.

**Dr. Castellino:** Thanks.

**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 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](https://LLS.org/PatientSupport). You can find this link and more in the show notes or at [TheBloodline.org](https://TheBloodline.org).

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