LEUKEMIA & LYMPHOMA SOCIETY®

THE BLOODLINE WITH LLS

A PODCAST FOR PATIENTS AND CAREGIVERS

Episode: 'Patient-Doctor Perspectives: Resilience in Relapsed/Refractory Hodgkin Lymphoma'

Description:

In this episode, we speak with Dr. Matthew Matasar of Rutgers Cancer Institute, and Elizabeth Stone, who was diagnosed with Hodgkin lymphoma in 2012.

Dr. Matasar discusses the current and emerging treatments for Hodgkin lymphoma. Elizabeth shares her story of resilience as a refractory patient throughout multiple treatments, and how she has navigated a life of hardships, joy, love and friendship while in a highly immunocompromised state.

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 with Elizabeth Stone and Dr. Matthew Matasar on relapsed/refractory Hodgkin lymphoma. Elizabeth has been a refractory Hodgkin lymphoma patient since 2012 and since that time has had over ten mainline therapies, including two stem cell transplants and clinical trials.

Dr. Matasar is a hematologist/oncologist and the Chief of Blood Disorders at Rutgers Cancer Institute in New Jersey. His research is focused on finding new and better ways to treat lymphoma, particularly high-risk aggressive lymphomas and certain uncommon types of non-Hodgkin lymphoma. Dr. Matasar is committed to ensuring his patients receive the best treatments delivered in the best ways and to be a partner and advocate to guide them through what can be a very difficult time.

LEUKEMIA & LYMPHOMA SOCIETY®

In this episode of our *Patient-Doctor Perspectives* series, we will be discussing the latest advances in Hodgkin lymphoma and the experiences of one patient through multiple treatments. Welcome Elizabeth and Dr. Matasar.

Elizabeth Stone: Hi, Elissa, thanks.

Matthew Matasar, MD: Thank you.

Elissa: So, our episode today is on relapsed or refractory Hodgkin lymphoma. Dr. Matasar, let's start with you. Could you tell our listeners about this diagnosis?

Dr. Matasar: Sure.

Hodgkin lymphoma is a form of lymphoma, or cancer of lymphocytes or of the immune system. And while there's many different types of lymphoma, Hodgkin lymphoma is a unique one, hence it being differentiated from all the others, which collectively are called non-Hodgkin. Hodgkin lymphoma can affect people at any ages, although it's more common in younger or older people and not so much during our middle ages.

It's considered an aggressive lymphoma, which means that if left unchecked or untreated, it tends to grow quickly and can be dangerous or even life-threatening. But it's highly treatable and often even curable with modern treatments.

Elissa: Now, we mentioned relapsed and refractory. Of course, I think most patients listening will understand the word relapse, but could you explain refractory?

Dr. Matasar: Sure. So, we tend to group relapsed and refractory or R/R in the medical literature into this one bucket; and this just means people that were failed by their first course of treatment, whatever that was, whether it was older chemotherapies, newer chemotherapies, chemotherapy with radiation, what have you.

Many times, after completing that first planned course of treatment, the disease will have been cured. Sometimes it goes away and enters into remission, meaning that

the scans and tests at the end of treatment show no sign of any leftover lymphoma. But, unfortunately, later on the disease shows up again. That's called relapsed.

Contrast that to refractory, which means that you've completed your first treatment; and the end-of-treatment testing shows, unfortunately, that the disease didn't go away but that it's persisted through that treatment or was refractory to that treatment.

Lizette: So, what are the common signs and symptoms? What generally brings someone into the doctor to be diagnosed?

Dr. Matasar: The typical signs of newly diagnosed or new onset classical Hodgkin lymphoma are definitely very well described. There's very common ones, things like fevers that have been unexplained by infection or drenching night sweats or unexplained weight loss. Another very common symptom is itching, which can be either part of the body or your whole body without a rash, without other causes; and that can be quite debilitating.

And then another which is less common but very specific for Hodgkin lymphoma is what's called alcohol-induced pain, which is after having a drink – beer, wine, spirits, doesn't matter – you'll get a burning or aching sensation in the area where the Hodgkin lymphoma underlies it with swollen glands.

Elissa: Elizabeth, could you tell us what signs and symptoms you had? What led you to being diagnosed with Hodgkin lymphoma?

Elizabeth: So, I actually didn't have almost any of the classical signs. I didn't have the night sweats, the fevers, the weight loss. Conveniently for diagnostic purposes, we found a lump in my right armpit that I couldn't explain from anything else and, of course, had it tested. Originally, doctors thought it might be a lipoma, it might be breast cancer. We weren't really sure what it was. But eventually with a biopsy, they determined that it was classical Hodgkin's lymphoma.

Lizette: Elizabeth, since your diagnosis in 2012, you've had several treatments. Can you tell us about those and how they went?

Elizabeth: Yeah, my entire life has been treatment for the last 12 years. We're just a month away from my diagnosis date, so that anniversary is coming up soon.

Traditional chemo to start the first-line treatment that cures the large majority of Hodgkin's patients. Followed by an autologous stem cell transplant, which is where they harvest your own stem cells, wipe your body with basically the nuclear grade chemo that they give you for a stem cell transplant. Put your own stem cells back in, hoping to reboot the system. When that failed, a series over five or six years of different immunotherapies, clinical trial drugs, a lot less toxic than traditional chemo. Occasionally, combinations, cocktails with a traditional chemo-active agent. And then in 2020, when we had run through the enormous list of possible treatments that had not resulted in any remissions, we did a secondary stem cell transplant, an allogeneic stem cell transplant with my sister as my donor. And when that failed, we did more immunotherapy; and now I am on my first oral chemo.

Lizette: Oh, you mentioned that you were on clinical trials?

Elizabeth: Yes, a couple of different ones at different locations. A few from my main specialist in New York. One at the Children's Hospital of Washington, DC. And then a few drugs of varying levels of FDA approval process that were probably much smaller scale trials being done at either my local or my specialist oncologist.

Lizette: Sure, and how are you feeling now?

Elizabeth: Right now, I feel pretty good on the cancer front. I just got some PET scans back showing that the oral chemotherapy is working, which I did not expect would be the case.

Elissa: Yay.

Lizette: Great.

Elizabeth: It's really great news except, at the moment, I'm very cranky because I broke my wrist, which is the fourth bone break that I've had in three years due to the ongoing damage to my bones from all the different treatments that I've been on. So, my body on the inside is a very old lady, not a 36-year-old healthy lady. And she's running ragged, even when we're at a good place with treatment, scans, etc.

Lizette: Have you had any other side effects due to the numerous treatments that you had?

Elizabeth: So many. So, we know that I have bad bones. That also means that I have really bad teeth. So, I'm getting my second crown. I've had two root canals. I have so many cavities. Every time I go to dentist, it's at least three. So, six a year cavity-wise.

I had really bad neuropathy in my hands and feet. I still get cramping in my hands if I try to write or do any delicate fine motor work. My feet and my lower legs are just a disaster zone due to the neuropathy. My gait was altered. My calves tightened. I don't have flexibility that I once did. That's what led to me breaking my foot three times – a combination of weak bones and adjusted gait due to neuropathy.

My GI (gastrointestinal) tract is all sorts of fun after so many treatments and especially the two stem cell transplants. I went into chemically induced menopause ten years ago. So, I've been infertile for a decade and just in a state of fun post hormonal, postmenopausal hormonal flux.

Elissa: Now, Dr. Matasar, Hodgkin lymphoma has a very high five-year survival rate at 89%, currently. Oftentimes, patients have said that their doctor told them it was a good cancer to have because it's so treatable. Why does some patients like Elizabeth not get into and remain in complete remission with these various therapies?

Dr. Matasar: So, the first thing to say to that, anybody who has just heard Elizabeth's story can refute this idea that Hodgkin's is the good cancer. It pains me to hear that. I understand it comes from a place of kindness where a doctor is trying to encourage and give hope and support, somebody facing a new diagnosis of Hodgkin lymphoma. But, to call this a good cancer is, obviously, a farce. There is no good cancer.

That being said, you're right. Many patients are cured of their Hodgkin lymphoma with our modern treatments. You quote a five-year survival percentage with modern treatments, which is accurate; but five-year survival doesn't even begin to tell the whole story, right, because on that sheet of paper, Elizabeth's a five-year survivor many times over. But she's living with cancer and living with all of the, aftershocks from treatment after treatment and trial after trial and course after course. So, five-year survival is part of the story but never the end of the story.

Why are some cured and some not? It's really important and a good question. We don't know the answer entirely.

We have started to delve into the actual cellular level of genetics of Hodgkin lymphoma to try to understand what's going on. And there are some adverse biological characteristics that differentiate some cases of Hodgkin lymphoma from others. But there are people with high-risk features who are cured, and there are people with lower-risk features who are not.

Lizette: Now, Elizabeth, what has the emotional impact been for you as you've gone through so many treatments without getting into that complete remission?

Elizabeth: What has the emotional impact been? I mean this is the crux of the matter, right? When you are a refractory patient, you're being told over and over again that your cancer is back, that it's growing. You're looking at the list of treatments and seeing them dwindle as you fail each one in turn. You are suffering the secondary effects like I have been with menopause, with bone breakages, with

lung capacity, a side effect I forgot to mention from the very first chemo that my lungs are weak and that I've had pneumonia a couple of times that's landed me in the hospital.

It is a constant walking on a very high balance beam where on one side if you fall, you're going to die; and if on the other side you fall, it's going to be some good months, but for how long? How long before you're back teetering on the balance beam thinking, this is it? This is the time. This is the one that's going to kill me.

When you have pneumonia and you're like, "Oh, crap, this pneumonia might be the thing that kills me," being here in the hospital. Constant fear. Constant feeling trapped. Constantly feeling like I can't build anything in my life because I need to be able to knock it down potentially every three to six months to accommodate a new treatment or a flight to a specialist or in most recent years talking with my husband and my family to say, "What happens if I need to go to Seattle for a year because there's only one trial and it's there? What happens if I need to live completely out of state, the way that I did with my allogeneic stem cell transplant in the summer of 2020, when we literally cannot have any other caregivers come help us, nor can we have visitors because of the pandemic?"

Speaking of that, another side effect, of course, is that I am, and still continue to be, extremely immunocompromised, given the last four years of the pandemic. People with blood cancers, people who have had transplants, organ transplants, or stem cell transplants, these are people high up there on the list of very susceptible immunocompromised patients for viral infections like COVID, where we do not have any sort of prior interaction out of childhood or a childhood vaccination level.

So much of the past four years, my husband and I have lived in the highest state of isolation out of anyone that I know besides the people I read about in sympathy articles in the newspaper occasionally. Up until the spring of 2023, we weren't going into public indoor spaces with masks on for more than 15 minutes, because I didn't

trust that the mask could protect you for more than 15 minutes. And only in the last year have I gone on planes again, started traveling, still wearing the mask, still not eating indoors with people unless they've isolated in advance. And it's all terribly taxing because I live in a body made of glass that I know is going to fail at some point, and I predict strongly will fail before I'm 50.

But it's a question of how much joy and adventure and normalcy do I get to experience in the body without putting it at such great risk that I will not be able to enjoy additional joy in life and adventure a couple of months, a couple of years into the future because I tax the body too hard.

So it's rough. It's pretty rough. And there are wonderful moments. There have been great things I've done since being diagnosed, but it's a huge roller coaster. It's an enormous roller coaster where your seatbelt could come flying off of you at any point.

Lizette: Yeah.

Elissa: You talked a little bit about COVID kind of changing everything for you and being very severely immunocompromised. Now, you and I have known each other for six years, having met at a young adult cancer conference called CancerCon; and so, I've seen you go through this whole process, and of course, me too as a blood cancer survivor, but you in particular. And there was one particular reason, and that was the vaccine. Watching you react very differently to the vaccine than I did, the COVID vaccine. Could you talk a little bit about that?

Elizabeth: Yeah. So, I'm not sure if you were as well, but I was a volunteer participant in a study that LLS was doing about vaccine efficacy for blood cancer patients. And they gave us orders to have blood testing done to see what the antibody count was post-vaccine back in 2021 when the vaccine came out.

And I got vaccinated. I was so excited. I started seeing people inside, thought that life was going to go back to normal. Did the blood tests and, I think it was a range of

something like less than 2. Right, unmeasurable to, like, 2000. And I was at less than measurable. My antibody count was not even something that could be tracked. I was in the bottom like 3 percentile of all vaccine respondents in terms of the strength.

So, I had to treat myself like I was unvaccinated; and in a world where US policy was entirely based on if you get vaccinated you will be safe, and you've done everything that you can do, I had to come up with alternatives that would protect me like staying in my house, like only seeing people after they had stayed in their own homes for seven days before we came for Christmas or Thanksgiving, like not hanging out with my friends to watch a movie indoors, even with masks on.

I tried to do everything that the science told me would present zero risk because at that point I was pretty fresh out of my stem cell transplant and hoping that I had finally been cured; and I wanted to keep the delicate little glass body that everyone had been cheering me on to finally find a cure. And when I thought I had it, they suddenly said, "What are you doing at home? You need to come out and live." And I would say, "Well, you really wanted me to be alive, and I'm staying alive by staying free of COVID. I don't see where the problem is here; and I don't see why you won't help me more."

Elissa: Yeah, now that all changed though with this recent booster, didn't it?

Elizabeth: The booster started giving some efficacy, yes, and that was great news. It gave me a little bit of hope that the booster had actually gotten me to, if not the fullest strength, then at least a partial response. And that plus three years of really traumatizing intense isolation and additionally, my newest relapse in 2023 where the post-transplant immunotherapy finally failed. It was just, "You know, body, I'm not even going to try to protect you nearly as much. You don't deserve it. You're going to fail anyway. I might as well go out and live my life."

Still haven't gotten fully to a place of unmasking entirely because, you know, I'm not a fool. But, yeah, pushed me out the door really intensely and almost wished that that had happened earlier.

Elissa: Yeah, I have to say it has been so fun to watch you finally be able to go out and, go places and live a life.

Elizabeth: Thanks.

Elissa: Dr. Matasar, Elizabeth talked quite a lot about some various treatments. Could you tell us about the current treatments for Hodgkin lymphoma and then what happens when patients don't respond to treatment like Elizabeth?

Dr. Matasar: Yeah. I mean, so you've heard already from the expert that the truth is that there are a number of different treatments that we have. Most patients will be treated when they're first diagnosed with a combination of chemotherapy of some sort or other. The one that Elizabeth undoubtedly received back in the day, reading between the lines, was a program called ABVD. And this was traditional treatment even back when I was in medical school, back in the day and, and up until quite recently was the standard of care for patients newly diagnosed with Hodgkin lymphoma worldwide.

We have made progress since then, I'm happy to report, and seeing that we're able to improve on outcomes by using not just pure traditional older chemotherapies but newer medicines that can be incorporated into those programs has really improved outcomes.

So, ABVD was replaced or supplanted by a combination where the bleomycin, the B in that program, the drug that injured Elizabeth's lungs, has been substituted for a newer medicine called brentuximab vedotin or ADCETRIS®; and this is a newer medicine, the antibody drug conjugate that has been proven, when used in this combination, cures more people and people live longer than if they were treated traditionally.

We're trying to push even beyond that, and there's a very important trial that we're awaiting final and mature data from that compared that newer BV-AVD or A-AVD program that has been our now standard to a program where the brentuximab has been substituted for an immunotherapy, a type of treatment called checkpoint inhibitor therapy. And these are a family of medicines that are very effective in treating Hodgkin lymphoma. They don't directly kill cancer cells. What they do is they remove the ability of Hodgkin lymphoma to hide from our immune systems. And by removing these shields, enable our immune system to attack the cancer cells.

And these treatments are now approved for patients who have been failed by chemotherapy, people who have been failed by stem cell transplantation. But we're asking the question whether we use them as part of the initial treatment, whether people will be cured more often and live longer than we do currently by saving it for when we need it after traditional treatments have failed.

Lizette: Now Dr. Matasar, are there also treatments for the many types of side effects that Elizabeth has talked about? I know that neuropathy is a big one that a lot of people ask about.

Dr. Matasar: It is and you're absolutely right that side effect management is so much a part of taking care of people living with cancer. And the first thing to say is that the most important part of that is having a good relationship with the oncologist, a trusting relationship where you listen to each other, you trust one another to take it seriously, and to try to help.

Every side effect has treatments that we know can be beneficial. Neuropathy is a tricky one, and there's different types of neuropathy. There's neuropathy that is what we call numb neuropathy where it's just a loss of sensation. Motor strength is fine, coordination is fine. Just numb. That's very, very hard to fix with medicines.

Painful neuropathy, worse, right? It's not just numb, but it hurts, it burns, or stabs. Painful neuropathy can be debilitating, and this is a situation where medicines can be

helpful; and there's a number of different prescription medicines that can be used that are good at damping down that burn, that pain that can be associated with neuropathy and that help many patients.

But there's other things other than medicines, right? There's good evidence that acupuncture and other complementary medicine approaches can help with neuropathy, as well as other side effects like nausea and fatigue. So really, in an ideal world, the relationship between cancer patient and cancer doctor is one of mutual trust, listening, and a recognition of the importance of helping people feel as good as possible for as long as possible, whether they've been cured of their disease or living with their disease so that they can have a joy that Elizabeth was speaking to that she feels is sometimes lacking from her life.

Lizette: Right. And Dr. Matasar, I know that you must be particularly excited about some of the new emerging therapies for Hodgkin lymphoma, as well as quality of life getting better for Hodgkin lymphoma, specifically taking away the bleomycin for younger folks. So, what are you really excited about that's coming up that you see in clinical trials or these emerging therapies?

Dr. Matasar: So much of my work is focused around this idea of wanting to help people live longer and also feel better. And it's gratifying to see that we're making progress doing just that in Hodgkin lymphoma.

We have newer treatments that are coming online that achieve just that goal, right? That are able to be very effective even when patients have been failed by chemotherapy, even by our current available immunotherapies. But these treatments should also be not only more effective but also less toxic.

And that's sort of the story that Elizabeth tells, right? She's been on both standard chemotherapy programs, as well as clinical trials that fit your exact wording, Elizabeth, that it was like milder or gentler treatments.

And oftentimes, it's what we look for in experimental therapeutics. That has both the promise of activity against the disease and hope. We can offer that and at the same time offer patients, the hope of living well with their disease and living well with their treatment.

In terms of what's on the immediate horizon for us in terms of newer treatments for Hodgkin lymphoma, I would say that a lot of it continues to focus around the questions of, how do we best harvest and enable the immune system to do our work for us? So, there are a number of approved immunotherapies already. We're now running a lot of clinical trials where we're combining approved immunotherapies with new immunotherapies, going for these one-two punch approaches where 1 plus 1 might equal 3 or maybe even 5. And by trying to target immune system enhancement and activation in complementary and synergistic ways, maybe we can help patients that have been failed by more simplistic immunotherapies.

There are also new antibody drug conjugates that are coming around, trying to deliver new toxins in a safe and effective way directly to Hodgkin cells, while sparing most of the body the side effects of those toxins that are stapled to the immunotherapy or the antibody in this case. So, there's a lot of creative work being done to try to help people live longer and also live better.

Elizabeth: I just want to echo Dr. Matasar and say that immunotherapies are incredible, and there has just been huge numbers of advances, even since I was diagnosed in 2012. When I was diagnosed, I was a first-line therapy patient. But no one was talking to me about immunotherapies, even after I relapsed. It was like, "Okay, well we did the chemo. Now we're going to do the auto[logous] stem cell transplant." And then all of a sudden in the mid-2010s, immunotherapy started becoming available in trials, starting to get FDA approved. And the best of my treatment years, having been on at least one treatment every single year for the last 12, have been the years when I've been on the immunotherapy.

I've had almost no side effects. My quality of life has been really high, and so many things can be accomplished without pain. And, as someone on the refractory side of things, that is the dream to be kicking the cancer back and not suffering yet again. So, yeah, immunotherapy's great.

Elissa: Elizabeth, you had said something to me several years ago – I think this was pre-pandemic – about wanting to share your story and to do fundraising and assist in that fundraising by sharing your story to hopefully, fund these future treatments so that maybe there will be one out there that will be the one that works for you.

So, remembering that and then hearing about these emerging treatments from Dr. Matasar, what are your thoughts on the future?

Elizabeth: Well, first of all, I've probably been doing a really good job at selling myself as a positive voice. I strongly believe in research and funding. I want to be that voice. Sometimes it's just really hard. You look at the future, and you're like, "Ah, the future." Yes, I just see pain, and I see a life where my friends are having kids, which I will never be able to do, and they're growing in their careers, which I went into medical retirement; and it just feels like a huge disparity. Right, like the future feels like being at a crossroads and going one way where the people I hang out with are all other retired ladies of the life of cancer center doing gentle Zumba together. And all the people I grew up with are having a totally different life that I will never have.

In terms of the future of treatment, I am very hopeful about the future of treatment for Hodgkin's, for a lot of other blood cancers, especially for refractory and relapsed patients. With immunotherapy, with advances in genomic understanding and potentially individualized medicine, especially for blood cancers, which are systemic and not just tumor-based, I feel like the sky's the limit. And I feel very lucky to have been diagnosed at one of the pivotal times of change where immunotherapy has emerged as a kind of savior drug.

My hope and when I'm feeling more positive, what I tell people is that, hopefully a lot of cancers, mine included, eventually will be more like diabetes, where it's a huge pain. It causes massive damage to your body, but with medication, it can be manageable. It can be worked with instead of fought against, right?

I think that's where I hope a lot of cancer treatments will end up. That this is a normal thing that your body does. We've taken care of so many other disease and causes of untimely deaths from history that everyone will probably have some cancer; and you live with it. There's a medication for that. It has these side effects. That's just a tolerable portion of your life as opposed to the constant running back and forth between, "I'm fine. I'm going to go on a $10,000 trip around the world" to, " I'm going to die in the next three months; and I need to say goodbye to everyone and make sure my husband has my passwords."

There's, going to be a middle line, right, where it's like, "Okay, this is going to be bad for a year." But then it'll be okay, even if it is a scarier cancer or if it is a relapse or refractory case like mine.

Lizette: Wow, I just want to thank you, Elizabeth, because really sharing your story has been inspirational because a lot of patients who hear the word refractory may not think that there's a future. And I love that you're here sharing with us, letting people know that there is a future. And I think that you bring a lot of people hope.

And Dr. Matasar, I'm going to ask you about hope right now. Our final question for you today. On our patient podcast home page, we have a quote that says, "After diagnosis comes hope." What would you say to patients and their families to give them hope after a diagnosis of Hodgkin lymphoma?

Dr. Matasar: The first thing to say is that the hope is real, right? We started by talking about Hodgkin as a highly curable disease. It's not the good cancer. We've dispelled that myth. But it's a highly curable disease, and most patients facing this diagnosis, unlike Elizabeth's story, most patients' stories are simpler. They get

diagnosed, they receive a course of treatment, their disease goes away and never comes back. That's not to make light of that experience. Change is everything. And even as a cancer survivor, your health needs and your health focus is going to be different than it was before this experience.

But that's not to say that that's a hopeless situation. It's not. It's a hopeful situation. And we go into these experiences with the expectation that good things are going to happen.

And then you have stories like Elizabeth, where good things haven't happened very often. There's been a lot of challenges and a lot of setbacks. But even there, you've heard a story of resiliency and of life and, yes, it's had its ups and downs. But it's also been one full of friendship and laughter, and love, and all the things that we want for our lives and for the lives of those that we love.

Living with cancer doesn't need to be a hopeless situation. It can't be a hopeless situation. It has its challenges, and those challenges can enrich your life; but they can also change your life. So, go into the experience with an open mind, hold that those that you love close at hand, and be ready to walk their road with others, and be ready for good things to happen.

Elissa: I love that.

Now Elizabeth, a similar question to you based on the quote, "After diagnosis comes hope." Based on your cancer experience, how would you complete this sentence? "After diagnosis comes-"

Elizabeth: I would say after diagnosis comes just like a tsunami where it's so many emotions. It's so much information. It's so much change. And I think most people, once they're able to get past the initial terror, once they're starting their treatment, feel like they're on the path, don't get as much education right off the bat as maybe they could. Maybe they should.

As I've mentioned, as Dr. Matasar has mentioned, because I think a lot of doctors don't want to terrify you when you're already so scared by the words of your diagnosis. They don't want to scare you with all of the what-ifs and the edge cases. Even if you are someone who goes through your initial treatment, you're in remission many, many years, it's going to be a lot. It's going to be a lot of things that you have to learn, a lot of questions that you have to ask and advocate for.

The oncologists I've worked with have not been as focused on sort of the holistic person on side effect management. It's been a lot about, well, let's get that disease out of you as best we can; and it's going to be a roller coaster for everyone of varying intensity with what you need to learn, what side effects you couldn't anticipate, how your body's going to change, what your career is going to look like, what kind of accommodations you may need to ask for, and that information is all out there, even if currently the way it's set up, requires you to be the one to go out and find it all.

So, just know that it will be a lot, but it is out there. The information is out there, wonderful online advocacy groups, support groups. They are out there. You just may need to ask for a little bit of help to get connected. And once you get connected, hopefully that will give you the companionship and that sense of togetherness that you're not facing it alone because you're not facing it alone. And with better advances in medicine, better advances in telecommunications, etc., you can find other people who have a similar story, get the information you need, get the assurance that, yeah, a lot of things are going to happen. It's going to be a tsunami, but there's going to be lots of resources out there to help you sort of ride the wave as much as you can.

Elissa: That's great. Wonderful advice.

Thank you so much, Elizabeth and Dr. Matasar for joining us today and talking all about relapsed/refractory Hodgkin lymphoma. We really appreciate, Dr. Matasar, you talking all about this disease and all the treatments, emerging treatments, and then Elizabeth, of course, for sharing your story. And I hope other people who are

relapsed/refractory are listening to this and getting inspiration from it. And, that there is hope for the future to just keep going and keep trying treatments. And so, again, we really appreciate both of you for joining us today.

Dr. Matasar: And thank you, Elizabeth, for sharing your story, the bravery that it takes to be willing to share something so deeply personal is really inspirational.

Elizabeth: Thanks, Dr. Matasar. I think a lot of people will tell me that I'm brave, and the answer is like it's easy to be "brave" when you're constantly facing the gun, facing the bullet that might finally knock you out. But, I'm more than happy to talk about the good, the bad, and the ugly with my 12-year history of treatment because I think a lot of people out there either don't know or don't want to think about it.

And I have to think about it, and so I might as well give everyone else that information, as ugly as it may have been.

Elissa: And just like all of our podcasts, we're looking to find connection. And I think those relapsed/refractory patients can also, often feel left behind with a disease like this that so many people respond to the first treatment and do very well with. And so, sharing your story is so important so they understand again that they are not alone.

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.

Did you know that you can get more involved with *The Bloodline* podcast? Be sure to check out our Subscriber Lounge where you can gain access to exclusive content, discuss episodes with other listeners, make suggestions for future topics, or share your story to potentially be featured as a future guest. You will also receive an email notification for each new episode. Join for free today at TheBloodline.org/SubscriberLounge.

LEUKEMIA & LYMPHOMA SOCIETY®

In addition to the Lounge, we could use your feedback to help us continue to provide 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 completely anonymous, and no identifying information will be taken. However, if you would like to contact the LLS staff, please email 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. You can find more information on Hodgkin lymphoma at LLS.org/Lymphoma. 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.