LEUKEMIA & LYMPHOMA SOCIETY®

THE BLOODLINE WITH LLS

A PODCAST FOR PATIENTS AND CAREGIVERS

Episode: 'Dr. Ninan Explains Diffuse Large B-cell Lymphoma (DLBCL)'

Description:

Dr. Mary Ninan speaks to Alicia, Lizette, and Edith about the most common subtype of non-Hodgkin lymphoma (NHL), known as Diffuse Large B-cell lymphoma (DLBCL). With over 70 subtypes of NHL, the priority when Dr. Ninan sees a patient with lymphoma is to confirm which subtype the patient has been diagnosed with in order to determine the best treatment plan. Dr. Ninan explains how lymphoma is staged, and various treatment options are discussed. The doctor also mentions how she always encourages patients and caregivers to ask questions and clarify the points that they do not understand in the treatment plan, as well as welcomes questions about how patients can manage their side effects. Also, in this episode, Dr. Ninan talks about one of the most exciting developments in the treatment of diffuse large B-cell lymphoma in recent years.

Transcript:

Alicia: Welcome to *The Blood Line with LLS*. I'm Alicia.

Edith: I'm Edith.

Lizette: And I'm Lizette. Thank you so much for joining us on this episode.

Alicia: Today, we will be speaking with Dr. Mary Ninan. Dr. Ninan is part of the network of experts at Georgia Cancer Specialists, affiliated with the Northside Hospital Cancer Institute.

Dr. Ninan is board certified in medical oncology, hematology, and internal medicine. With experience in both the academic and outpatient clinical settings, Dr. Ninan is dedicated to advancing oncology research.

Thank you for all you do, and welcome, Dr. Ninan.

Mary Ninan, MD: Thank you for having me.

Alicia: Of course. Now before we jump into today's topic, which is DLBCL, diffuse large B-cell lymphoma, we like to get to know our speakers a little bit more. So, what brought you to the field of medicine, specifically hematology and oncology?

Dr. Ninan: My father was a physician so, as a child, I was truly fascinated by what he was doing. So early on I had decided that I wanted to do medicine. And, unfortunately, I lost my father in my childhood and, again, so I felt that I needed to continue it as a legacy, and I pursued medicine as my career.

Unfortunately, during my time in medical school, there were several of my extended family members who were diagnosed with cancers. And, at that time, cancer was considered to be something without much of a good prognosis. And I started reading up and researching more about different types of cancers, and I started getting interested in mostly the hematology malignancies. And during my residency I had the fortune to do research with Dr. Waller at Emory University in bone marrow transplant end, that, again, solidified my interest in hematologic malignancies and hem/onc in general. So, I decided to pursue the Fellowship and here we are.

Alicia: I'm So sorry to hear about your father. I'm sure that he'd be very proud of you.

Dr. Ninan: Yes, I hope so.

Alicia: Dr. Ninan, on MDatl.com there is a quote from you, and you said, "I love working in oncology primarily because I'm able to help my patients choose and navigate a complex treatment plan, and achieve the best outcome possible." And I'm sure that when the patients come in, you know, and they are about to be told they have a cancer diagnosis, which is, one of, if not one of the scariest things that someone can hear. How do you relay that information to them, specifically, how is someone diagnosed with lymphoma, and what is the diffuse large B-cell lymphoma, for someone that you have to explain the diagnosis to?

Dr. Ninan: So, for every patient that gets a diagnosis of cancer, it is the most life changing episode that can happen in their life. So, I take it a priority to explain what the diagnosis means and what the treatment options are available to them. And how best we can great so that the outcomes can be achieved, at the same time maintaining a quality of life.

So, in oncology I feel that there are standard treatments, but every patient will respond to the treatment in a unique way, depending on how they tolerate the treatment and how they manage their side effects.

So, as the physician, I make sure that the patient and their caregiver understand what it means to have a particular cancer and what they should expect during the treatment so they're well prepared to deal with their side effects.

In reference to the diffuse large B-cell lymphoma, it is one of the most aggressive lymphomas but, at the same time, if you treat it properly with chemotherapy or radiation therapy, there is a good chance of attaining a cure in the majority of the patients.

So, I try to emphasize that with the patients and that gives them a hope in continuing with the therapy, which is not very pleasant for most of the patients. The patients who come to me are mostly devastated by the diagnosis and they are scared, they are anxious, they do not know what to expect. So, it will take a few visits before I can get them to the comfort level where they can trust me, and they can proceed with the planned treatment.

Alicia: Absolutely. And so, what are a few of those signs and symptoms of a DLBCL patient?

Dr. Ninan: So DLBCL, or diffuse large B-cell lymphoma, is a type of non-Hodgkin's lymphoma. If you think about lymphoma, it is a cancer of the lymphocytes which is a type of blood cell. So, the lymphoma is broadly classified into Hodgkin's lymphoma and non-Hodgkin's lymphoma, and diffuse large B-cell lymphoma is one of the commonest forms of non-Hodgkin's lymphoma.

Since it is a cancer of the lymphocytes, most of the patients present with symptoms from enlarged lymph nodes, which are glands that are present everywhere in the body. Some of the patients may have lymphoma involvement involving other organs like liver or spleen or bone marrow, or even the bones. So, the symptoms of the lymphoma are usually related to which part of the organ system is involved with the lymphoma.

If the patient has lymph node involvement in the neck, they may present with a swelling or they may have pain if the lymph nodes are in the abdomen or maybe chest pain or trouble breathing. So, it all depends on where the lymph nodes are enlarged.

Some patients also may have additional symptoms like fever or weight loss or night sweats, which are called the B symptoms of the lymphoma. So, in general, it depends on which area of the body is involved.

Lizette: And how is diffuse large B-cell actually diagnosed? There's so many types of non-Hodgkin lymphoma, and I know it's so important to be diagnosed with the right, specific type of non-Hodgkin lymphoma that you have.

Dr. Ninan: Yes, you are right. There are close to 70 different subtypes of non-Hodgkin's lymphoma, and as a doctor who treats lymphoma, the priority when I see a patient with the diagnosis of lymphoma is to confirm that, or we know exactly which subtype of lymphoma we are dealing with.

There are indolent lymphomas as well as aggressive lymphomas and determining whether the subtype falls into the indolent category or the aggressive category determines what type of treatment the patient decides.

Lizette: Here at The Leukemia & Lymphoma Society, we have an information resource center where information specialists speak to patients and caregivers about their diagnosis and treatments. And a lot of times when we get calls, we do get patients saying, you know, I have lymphoma. And a lot of times they don't know what type of lymphoma they have. And I think one thing that we've always tried to tell people is to try to really find out what type, because the type really is what's dictating the treatment and the actual goal of treatment because isn't the goal of treatment for these aggressive lymphomas so much more different than the treatment goal for the indolent or the slow-growing lymphomas?

Dr. Ninan: Yes, you are right. In fact, for many of the patients that I see, I refer them to The Leukemia & Lymphoma Society and your website for more information and for support groups so that patients can gather information rather than just googling it and getting it from some random websites.

The indolent lymphomas and aggressive lymphomas have a different way of treatment and different.

Lizette: Goal of treatment, really, right?

Dr. Ninan: Different goal of treatment in the sense that in indolent lymphoma most of the time we do not have to treat the patient unless the patient is now symptomatic. But in aggressive lymphomas, unless we treat, the lymphoma can be life threatening.

So, determining which category the diagnosis falls into determines which treatment is needed for the patient.

Lizette: Sure. And I know that you touched on it before, but how specifically is diffuse large B-cell lymphoma treated?

Dr. Ninan: Diffuse large B-cell lymphoma is mostly treated with chemotherapy, usually a combination chemotherapy is used. The pneumonic we use is R-CHOP which is a combination of an antibody called rituximab along with four other chemotherapy medications. Sometimes the patients also will require radiation therapy based on how large the tumor is. There are several factors that go into determining whether the patient will need radiation.

The number of cycles of chemotherapy is also determined based on the stage of the disease and how advanced the disease is at the time of diagnosis.

Lizette: A lot of people will say that they're hesitant to have chemotherapy because of all the side effects and because of how strong chemotherapy is. Do people with diffuse large B-cell lymphoma have different treatment options?

Dr. Ninan: Because it is an aggressive lymphoma, you need chemotherapy to put the disease in remission. In older people, typically, what we do is we use a reduced dose of chemotherapy, using the same drugs but at a lower dose so that they are able to tolerate it better. And even in those patients, we are able to attain a good response if the patient is able to complete the therapy. There aren't really any gentler chemotherapy regimens, if you will, but there are some modifications to the treatment that we can do so that we can attain a remission.

In some patients who cannot tolerate the multiagent chemotherapy, which is actually recommended in lymphoma, we can do palliative therapy to help with the symptoms. Sometimes radiation is also used in those situations to help with the symptoms in patients who cannot tolerate chemotherapy.

For my patients, what I try to educate them on is, how to manage the side effects, how to proactively manage the toxicities so that they are able to complete the treatment.

In some patients who have underlying cardiac disorders, or other health conditions, we may have to modify the chemotherapy to suit the patient better, and we do that quite often.

Lizette: And I know that patients and caregivers have been asking us all the time about CAR T-cell therapy, which is a newer type of therapy. And I think there's a few CAR T's that are actually approved at this point for diffuse large B-cell lymphoma.

Dr. Ninan: Yes, you are right. That was one of the most exciting development in the treatment of diffuse large B-cell lymphoma in the recent years. CAR T therapy stands for chimeric antigen receptor T-cell therapy, and it has changed the way we treat relapsed diffuse large B-cell lymphoma. And until we had this treatment, the options for relapsed lymphoma was truly limited.

What happens in CAR T therapy is T cells are collected from the patient and it is genetically modified so that it's activated, and then it's infused back into the patient's body so that these T cells, which are super charged T-cells, can go back and fight the lymphoma with their own immunity. So, it's actually a very neat way of trying to get your own immune system to fight the cancer.

Lizette: Definitely. I think a lot of people are very excited about, you know, new treatment options, especially for people who are relapsed and refractory from diffuse large B-cell lymphoma. Do most people get cured after the first treatment, or do you find that people will relapse?

Dr. Ninan: So, with the current chemotherapy, about two-thirds of the patients get cured with the first line of therapy. The issue with diffuse large B-cell lymphoma is the prognosis depends on the molecular subtype of diffuse large B-cell lymphoma. Right now, we divide diffuse large B-cell lymphoma into two major subtypes called the germinal center B subtype, and the activated B cell subtype.

Depending on which subtype you fall into, the prognosis can be a little different. We are doing several clinical trials to identify how best to treat the patients who have bad prognostic factors at diagnosis. There are several exciting clinical trials ongoing and, hopefully, there will be more new agents available in treating these poor prognosis patients upfront so that they can be cured in the first round of chemotherapy.

There are about one-fourth or maybe one-third of the patients who do not attain a remission with the first round of chemotherapy, and those are the patients that go on to get experimental therapies, clinical trials, or CAR T therapies or autologous stem cell transplantation.

So there is a lot of research going on using experimental therapies for new drugs that are targeted against antibodies, targeted against antigens on the surface of the

lymphoma cell, or newer agents which have new mechanisms of action, which could potentially improve the outcomes in all patients with lymphoma.

Lizette: That's good to hear. Definitely, good to hear. I know that here at The Leukemia & Lymphoma Society, we really encourage patients, as well as their caregivers, to have an open conversation with their treatment team about clinical trials and about clinical trials as an option for treatment at any point of your treatment path.

Dr. Ninan: Yes, you are right. Lymphoma and cancer in general have so many different options available and the treatment paradigm is changing every month or every day, if you will. So, it's always good to look out to new therapies and new treatment options, especially in patients who do not fit into the good prognostic markers. It's always good to look for clinical trials or new treatment availabilities.

Edith: Doctor Ninan, sometimes patients feel a bit timid when talking to their healthcare team. How important is it for patients to have open communication with their healthcare team?

Dr. Ninan: It is a very good question. You are right, a lot of the times patients feel that the more they ask questions, the healthcare providers may not like answering those questions, or they may be intimidated. I always encourage patients to ask questions and clarify the points that they do not understand in the treatment plan and also how to manage their side effects.

For example, with diffuse large B-cell lymphoma, when you are undergoing chemotherapy, you could have some easily manageable side effects from the treatment, but unless you know what to do about it, the patient might feel miserable about managing those, and they will not have a pleasant experience during the treatment.

Chemotherapy is never an easy experience to begin with, and if you add toxicities on top of that, it will only make the treatment more difficult.

It is also important for the patient to have a good understanding of the treatment options that are available at other centers if they would like to get a second opinion regarding their treatment plan. And that will make them be comfortable with their treatment plan, knowing that they have received the best care possible.

Edith: What are common questions you hear from patients and their families when told they have DLBCL?

Dr. Ninan: One of the commonest questions I hear is about the staging of the lymphoma. Even though lymphoma is staged from Stage 1 to 4, it doesn't really mean the same as in breast cancer staging or a colon cancer staging. So, when I tell them you have Stage 3 or Stage 4 lymphoma, it doesn't necessarily mean that we are talking about a Stage 4 cancer which is not treatable or curable. That is a point that I try to reinforce at the beginning of therapy on what the staging means and how it will impact treatment.

In the treatment of lymphoma, staging actually represents which areas of the body are involved with the lymphoma. Stage 1 is just one area that is involved. Stage 2 has two areas on the same side of the diaphragm, which is the muscle that divides the chest and the abdomen. And Stage 3 would be when you have lymph nodes on either side of the diaphragm. Stage 4 is when you have other organs that are involved.

When you think about a solid tumor, Stage 4 usually means you have a cancer that has spread everywhere, and it's not considered curable.

Lizette: Yeah, it's so scary when, patients and caregivers, they don't have the whole full picture, like you're saying, and they're contacting us and they're asking us, about their disease. And they're saying, my loved one has Stage 4 lymphoma, and just, you know, really going into what does that mean. I think that's really important and a really important point that doctors and patients and their families should really have a discussion about because it's really scary when you hear that it's Stage 4, when they're really saying where exactly the lymphoma is located.

Dr. Ninan: Yes, exactly. So that needs a lot of explanation, and I actually show them pictures and try to explain what it means.

Another common question I hear is what are the long-term side effects of the treatment? The chemotherapy has some long-term effects that could potentially affect your heart, your nerves, and rarely can lead to some secondary malignancies. Those are very anxiety generating discussions that you have, and you are trying to cure one cancer, you're trying to tell them you could have some long-term complications.

So, trying to balance the risk and the benefits of treating versus not treating is a good discussion to have upfront.

Lizette: Definitely.

Alicia: Absolutely. Doctor, is there anything that you think we have not mentioned regarding DLBCL that you think patients and caregivers, and, and loved ones, would find beneficial to hear?

Dr. Ninan: I think the biggest message I have for the patients is that they have to make sure they have the right diagnosis, as we discussed earlier. We need to know what type of lymphoma we are dealing with. And even if it is diffuse large B-cell lymphoma, is it a more aggressive subtype where you need to look at treatments that are outside of standard of care? And you need to have a very open discussion with your treating physicians so that they can understand what to expect during the treatment and what your prognosis will be.

There are several new medications that are being tested in clinical trials, so there are options available for the patients. And then, having that knowledge will make them more comfortable. And always ask for resources that the patients and caregivers can turn to because there are so many social issues, economic issues, and other issues that society like The Leukemia & Lymphoma Society, American Cancer Society can help the patients with.

So, I think being educated in the diagnosis and the treatment options goes a long way in proper management of the disease.

Lizette: Sure. Anything that really can contribute to their treatment journey, that's also open for conversation with the treatment team, correct Doctor?

Dr. Ninan: Yes, that is absolutely right. Most of the time we forget to focus on the financial toxicity or financial concerns or social concerns, caregiver concerns, that can come along with treating the cancers. So, it is treating the whole person as a whole rather than focusing on the lymphoma. So those are all the conversations you will have to have with the care team.

I always tell my patients; no question is considered a bad question. If you don't ask about this, I would never know how we can help.

Alicia: Absolutely. And it's so great to hear a doctor say that because a lot of times people might think, if we were to get that information or that, suggestion from maybe a friend or a family member, they might think, "Okay, but you don't exactly know, what the atmosphere is like in the doctor's office." But I think it's so great to hear you, as a physician say it, because it opens the conversation up and allows patients and their families to know that there are two experts in that room, the person, like

yourself, who can give them the best treatment option and, also, the expert of themselves. They know exactly how they're feeling. So, bringing all of that to the conversation to really afford for the best treatment option for them.

Dr. Ninan: Yes, I agree. In my experience, having my multidisciplinary conversations regarding all aspects of their life and their treatment goes a long way in making sure that the patient is comfortable and getting the right treatment.

Everyone can give the same chemotherapy, but it goes a long way if you can support the patient along the way.

Alicia: Absolutely. We couldn't agree more.

Dr. Ninan, thank you so much for being part of today's episode and discussing DLBCL with us. And thank you for all that you do for patients and caregivers during such a, like you said before, a life changing moment of their lives.

Dr. Ninan: Thank you for giving me this opportunity for having this conversation with the patients and caregivers.

Alicia: Absolutely. And for those who would like more information about DLBCL or lymphoma overall, you can contact our Information Specialists Monday thru Friday, 9 AM to 9 PM Eastern time, by calling 1-800-955-4572. And they can provide support and educational information.

Thanks for listening.