

## THE BLOODLINE WITH LLS

A PODCAST FOR PATIENTS AND CAREGIVERS

### ***Episode: 'Diagnosed with Diffuse Large B-Cell Lymphoma (DLBCL). Now What'***

#### **Description:**

Being diagnosed with a blood cancer can be overwhelming. On this episode, Alicia and Lizette from The Leukemia & Lymphoma Society (LLS) speak with David, a diffuse large B-cell lymphoma (DLBCL) survivor, and Dr. John Leonard from Weill Cornell Medical College about David's lymphoma diagnosis. David and Dr. Leonard share helpful information for both newly-diagnosed and long-term survivors.

#### **Transcript:**

**Alicia:** Welcome to the bloodline with LLS, I'm Alicia.

**Lizette:** And I'm Lizette, thank you so much for joining us on this episode about diffuse large B-cell lymphoma, also known as DLBCL.

**Alicia:** Today we'll be joined by Dr. John Leonard from Weill Cornell Medicine in New York, New York, and David a DLBCL patient. Thank you both for being with us today.

Dr. Leonard, please tell us about your role at Cornell and what brought you to the field of medicine.

**Dr. Leonard:** So, I've been at Cornell for 27 years, at Weill Cornell and New York-Presbyterian Hospital in New York. And after training in internal medicine and hematology/oncology, a variety of circumstances led me to start to get involved in lymphoma, both clinical care and research. That was around the time, the mid-to-late 90s when monoclonal antibody-based therapy and particularly rituximab first came on the scene and so I got involved in clinical trials with new drugs and over the last 20-some years have been involved in a variety of aspects of, obviously, treating patients with lymphoma of all types, doing clinical trials with new drugs, understanding lymphoma from the molecular aspects in collaboration with laboratory partners, developing new and standard treatments looking at imaging such as PET scans, as well as outcome data on things like quality of life and other aspects of importance to lymphoma patients. So it's been a great area to work in and certainly one where we've been very happy to see so much progress over the last several years.

**Lizette:** We're so happy to have you on with us today. David, as a patient, being on the other side of the disease, how would you describe your life before diagnosis?

**David Banko:** I would say that my life before diagnosis was fairly hectic and fairly normal at the same time. I own a small business. I had two kids, one 11, the other one 9 at the time, so it was running around. It was a lot of coaching. It was a lot of sports. It was a lot of activities, a lot of business that goes along with that kind of life. I was very active, been a lifelong swimmer, had been training for half-marathons and doing triathlons before the time, so I had a lot of, lot of things on my plate. So, you know, I was constantly busy, always running around and always not having enough time throughout the day and just being normally busy.

**Alicia:** Right, right. So doctors, when someone like David comes into your office, someone who had such an active lifestyle, I know that you're not his doctor, but when someone like him does come, what, what's the first thing that you tell patients diagnosed with diffuse large B-cell lymphoma?

**Dr. Leonard:** Well usually patients, when they're diagnosed, are nervous. They're afraid. Maybe they have not yet had the diagnosis made, meaning they're ill, but we don't know why they're ill, and we haven't yet done a biopsy and need to clarify that. Maybe we know that they have lymphoma, but we don't know what type; and so because there are over 100 different types, you know, the, the expectations and the discussion with a patient will be very different, depending on those, those types. And then sometimes patients, many times they, you know, by the time they see the medical oncologist, they have a diagnosis. We have the pathology report. Maybe they've had scans; and so we, by that point, often know what to expect. So, you know, my, my goals tend to be to put the patient's mind at ease, that we have a plan, that we- Whether or not we know exactly how we're going to treat it, we have a plan as to what the next steps are to get our arms around the situation and figure out exactly what we're dealing with, what the best course of action is, and then, you know, really to tell the patient what the expectations are as far as treatment. And for diffuse large B-cell lymphoma, the most common scenario is that we are attempting and often successful at curing the disease and so that, in some ways, makes people a little bit more relaxed; but in other ways they're obviously nervous about the treatment and still the risks that they have. So I think our, our goal in our job is to really inform the patient on, on what the plan is, what we need to do, what the options are, what the expectations are, and then really set them on the right course so that they can have the best possible outcome.

**Lizette:** Great, sure. And, David, how did your doctor put you at ease when you were first diagnosed?

**David:** The, that was, that was an interesting scenario for me because I was first diagnosed from a ENT physician who I don't think was very experienced in the, letting

people know of, of what they've had with the disease; and it was more of a speculation at that time. That she thought, well, I think it's cancer is how I was notified of it. Not it is, not let's make sure it isn't, but I think it's cancer. So it was a very troubling time for me to get that and get that news as if, because I thought it was just a little something that I was having. But, you know, it was a, much more of a shock and, you know, I was, I was there by myself because I thought it was really nothing to be concerned about.

**Dr. Leonard:** I would add that that scenario that you describe is not uncommon because lymphoma has so many different types and because the outcomes are so varied and the treatments are so varied often the, often the, the surgeon who does the diagnosis or the intern, the diagnostic procedure, a biopsy or an internist who may have the information, really, they may not know that much about lymphoma. So often they say, well, you know, I'm going to send you to a good oncologist/hematologist who will tell you everything, but I'm not going to really tell you much of anything because I don't know much. And that, obviously, puts people in limbo; and I think it also often sends people to the Internet because they hear a diagnosis.

Their primary doctor that diagnoses them doesn't necessarily know much about what to tell them. And so while they're waiting for that second appointment, they may be obviously concerned and worried and seeking other information, so it can be a very scary time.

**Alicia:** Right.

**David:** And it very much was, but I must say when I, when I had visited the oncologist, that, that main goal of my physician was to first say, "Okay, here's what we think it is. Here's the course of action," and laid it out just as Dr. Leonard had, had mentioned. And that was a huge comfort because that, the time that I saw the ENT to the oncologist was about four days; and I did exactly what you said. I went to the Internet and tried to find out and, and educate myself as much as possible; and that was a dangerous and scary time because what you find out there is a lot of different, a lot of different information, oftentimes was conflicting, and, you know, it really was difficult for me not knowing where to go and just doing regular searches to try and find the information I was looking for. Again, was, was, was very confusing at first; but it was great to have that first conversation with the oncologist who had, you know, done the homework, decided what, you know, would be a good course of action and actually started that course of action fairly quickly which did put me at ease.

**Lizette:** And it must be so hard trying to look up, you know, what is lymphoma, what's non-Hodgkin lymphoma, and then now to know there's so many types of non-Hodgkin lymphoma. Dr. Leonard, can you go into some of the types of non-Hodgkin lymphoma?

**Dr. Leonard:** Sure. So, there are over 100 different types of lymphoma altogether, and I would say that there are more and more types being kind of subdivided or clarified as time goes by as we try to be more precise in the diagnosis and understand differences between groups of patients. The more classifications and subtypes we have, the better we can predict what's going to happen and decide on what the best treatment is. So about 10% of lymphomas in the US are Hodgkin lymphoma whereas about 90% of patients have the focus of our discussion here today or part of that, that non-Hodgkin lymphoma.

So non-Hodgkin lymphoma is much more common, and about 90% of non-Hodgkin lymphoma patients have B-cell non-Hodgkin lymphoma. So, I think of the lymph cells as kind of like the Army, the Navy, the Air Force, the Marines. They fight infections, and the B-cells are kind of the Army cells. They are the most common cells in some ways, but within the Army, you have tank drivers, paratroopers, infantry people doing different jobs. So, you have many different types of B-cells that do different jobs; and if the switches get broken in those B-cells, then that leads to a lymphoma, and depending on the type of B-cell, the broken switch leads to, or switches lead to a different type of lymphoma.

So, the three big categories of non-Hodgkin's lymphoma of the B-cell type are a group called indolent, a group called aggressive, and then a group more or less that I tend to call other, which is several less common types that have different characterization. So, the indolent and aggressive are the biggest categories. Indolent lymphomas, the most common of which is called follicular lymphoma, tend to be what we call chronic lymphomas where people live a very long time; and most of the time, though unfortunately not always, with indolent lymphoma it is something that people live with and often die with rather than die from, meaning it's managed chronically over many years, like diabetes or high blood pressure, in many different cases.

On the other hand, the aggressive lymphomas grow more quickly, often need treatment, sometimes aggressive, usually some form of more aggressive treatment, but the good news with aggressive lymphomas is that often, although unfortunately not always, but often they are cured with chemotherapy or combinations of chemotherapy with other drugs that can result in the patient going into remission, meaning we don't see any evidence of the lymphoma and ultimately being a cure, meaning it doesn't come back.

So the most common of the aggressive lymphomas is called diffuse large B-cell lymphoma and that is, I think, one of the focuses of what we'll talk about more today; but diffuse large B-cell lymphoma accounts for about 30% of people with lymphoma and, again, it is most commonly treated with chemotherapy, with combinations of other drugs and, again, is often curable but is something that we continue to work on to better understand how some patients do better and some patients do worse. What are the biologic differences between different types of non-Hodgkin lymphoma, of the

diffuse large B-cell non-Hodgkin lymphoma and how we can better use that to develop more effective treatments?

**Alicia:** Right, so, David, when you were speaking with your doctor about, you know, your treatment goals and your treatment journey, what part of that did you find most challenging?

**David:** There's lots and lots of waiting; and while you're waiting for tests, waiting for test results, that, that's, obviously, the, the hardest part through the process. And it's just one thing that you develop a lot of patience through this process and learning to wait and learning when's good times to wait and when you can push a little bit to get answers a little bit quicker than what is the normal.

**Alicia:** Right.

**Lizette:** And did you bring someone with you, a caregiver, to your first appointment with the oncologist because I know you went alone with the initial doctor?

**David:** Correct, my wife was my caregiver throughout the process, and she attended just about every appointment that I had, was there, and, and was really needed and, and very comforting. And, you know, when you have that process and when you have that, you know, that unknown, that fear, it's good to have somebody with you to help you, help calm you a little bit more.

**Lizette:** Usually when patients come in, if they come in with their caregiver, do you spend time with the caregiver or is it something that usually patients may not want the caregiver to hear?

**Dr. Leonard:** Well usually, you know, when you're seeing patients in the exam room or having a discussion, most of the time, you know, you're there with the patient and whatever family or friends are there with them, so we don't tend to send the family or friends out of the room. Although when we examine the patient or if there are sensitive things that the patient would prefer to have dealt with privately, of course, we would give that, that privacy.

But much of the time, and I would say most people, certainly when people are newly diagnosed it is quite common and I would say encouraged that a family member or friend come along. This can be somebody who just, you know, may have medical expertise, and so the patient wants them there. It, obviously, be a loved one who wants to hear the story as well and wants to be available as a support and resource. It can be someone who thinks of additional questions, just has a different memory of the visit because, obviously, a lot of things are running through the patient's mind and so it's hard to remember everything that's said. Maybe not always easy to logically come up with all of your thoughts and to ask all the practical questions and specific

questions because you're, obviously, as a patient, dealing with the emotions and the concerns that you have. So, having someone with you is, obviously, often a good idea; and I would say most people understand and appreciate that for various reasons. It can be very, very helpful and also somebody to take, take notes because I, I have no doubt, and I've heard patients say this, that, you know, in the car on the way home or the next day, you kind of, you know, replay some of the discussion and having somebody that's there that you can say did they really say that or what did they mean by that or, no, they really didn't say that, they said, "You know, let's focus on these issues," can be very helpful.

**David:** And let me add that during that process, having that caregiver when you're in kind of that state, you are not really thinking clearly, at least in my case I wasn't. So it was great to have somebody that could, you know, ask those questions that you want to but, you know, you just, you're just not in the state of mind to remember what you've talked about asking. So having that second person to ask the right questions, be able to retain some of that information because it's, it's very difficult to, when you're hearing all this news about yourself, that the ability to kind of, you know, listen to everything that they say and catch everything you say, just like Dr. Leonard was saying, is, is really good to have and to be really that person that could be the one that's making sure that all the things are being recorded, all the things are, you know, being retained and asking all of the right question.

**Alicia:** Right, and, like you mentioned, having a caregiver is extremely important; but in regards to having others to relate to how you're actually feeling and what you're experiencing, did you find yourself kind of utilizing support groups or anything outside of your wife or friends or family?

**David:** For the most part, we were using our support network, our support team that we called them, relying on them. We had a lot of people that would reach out to us. We had a lot of people that were doing their own independent research and trying to feed that to us. We had friends that had doctors that were in this industry that were providing support; they were reaching out. I mean we had a, we had a very fantastic team that we called them. And at the beginning when we were really trying to seek out all the information we could, we had a lot of people that were, that were doing that hands-on research.

**Alicia:** We've spoken to patients who say, you know, they're hesitant to discuss their side effects in fear of being taken off of treatment or they might feel that they're not being a good patient. Doctor, do you find that patients are open with you about their side effects that they're having?

**Dr. Leonard:** Well, I would say that it is very hard for doctors to actually gauge that, in part because, you know, obviously, we know about what we know about from the patient, from their family, what we see. But we don't know so much what happens at



home. Interestingly, there have been some various studies, various studies in the medical literature that I think to some degree is humorous, but to some degree it's sad, where you see people on a video go in the exam room and the patient and their family are there talking before the doctor comes in, and they're talking about this side effect, that side effect, the other side effect; and they have a whole long list of issues, and then the doctor or nurse comes in, and the patient doesn't raise any of those with them. Meaning that for whatever reason, it is pretty clear that there is either a hesitancy or a reluctance or something that in many cases, not all, but in many cases keeps patients from, from passing along all the information that they should be passing along to their treatment team, whether it's their doctor or physician assistant or nurse practitioner or nurse or other.

So I would say that under no circumstance should a patient kind of hide or minimize their side effects when they're meeting with their treatment team. Certainly, I think that's a good, good part and a good role for a family member or a friend to remind them, and I have patients all the time that have their spouse or someone remind them. "Don't forget to tell them, you know, you've been complaining all week that your back hurt. Why don't you tell him that your back hurt" or whatever it is. And so, I think that's very important. I also think it's useful for people to keep records or a notebook or a diary or something along those lines that they can bring with them to help to prompt them and remind them so that things aren't being missed.

**Lizette:** And what are the typical side effects from either the actual diagnosis or the actual treatments for Diffuse Large B-cell lymphoma?

**Dr. Leonard:** Well the, the most common way that lymphomas, in general, present themselves to patients are in large lymph nodes; and the lymph nodes are the glands in the neck, under the arms, in the groin. But you have lymph nodes draping various tissues inside the body, kind of like clusters of grapes; and so when those get enlarged to the size of plums or larger than that, in some cases, they can cause pain, swelling. You can notice the lump and say, "Wow, what's this?" if it's someplace you can feel it or see it; and that leads one to go to the doctor. Sometimes if it's internal, it can cause pain, back pain, stomach pain, cough, or breathing issues if it's in the chest, swelling in the legs if it's in the groin.

So usually patients either feel a lump or there's some symptom that is due to the mechanical aspects of having a lump in a place where it shouldn't be that leads to the diagnosis of lymphoma. So sometimes people have fever, chills, night sweats, weight loss. Those are very commonly symptoms that are asked about, although most patients don't have those symptoms. Some do but most don't, and most of the time it's feeling a lump or that lump causing some symptom that says, "Well, gee, I wonder why I have this cough. Maybe I better get an x-ray," and that leads to finding a lymph node in the chest that's causing the cough as an example.

The side effects of the treatment really depend on the treatment, and I think it's important for people to note that despite the treatment-related side effects, the lymphoma-related side effects can get better—meaning that if you, if you feel better as your lymphoma shrinks, despite the side effects of the treatment, the lymphoma aspect of things gets better.

So I would say that the, the main side effects of the treatment depend on the treatment. In diffuse large B-cell lymphoma, side effects can include low blood counts, fevers, infections. Some of the chemotherapy drugs, which I think we'll talk about in a few minutes, can give you hair loss, can give you fatigue, can occasionally affect the organs like the heart, can sometimes cause nausea. That being said, while many patients have kind of combinations of these symptoms, and there's a very long laundry list and most doctors give people literature or some paperwork that describes this in great detail and can be very scary, I would say that for some patients, these are severe side effects and for many patients these are manageable things that, while certainly not fun and could be quite discomforting in some situations, most patients get through this treatment and it's a temporary process.

So it really comes down to exactly what the specific treatment is, and I think it's very important that people talk to their doctor and their treatment team because they need to know exactly what treatment they're getting and exactly what the side effect profile of those specific treatments are and not make a decision on treatment or make an assumption about treatment based on what a friend had who had a different type of cancer and got a different chemotherapy had, and assume that the same thing's going to happen to them because it, obviously, may not. So you really need to know the details of your specific situation.

**Lizette:** And in speaking with David, he's not experienced many side effects, which is amazing and impressive, and most of the people listening may think, you know, how is that possible since we always hear about ways to manage side effects. Doctor, have you treated people of similar experience to David?

**Dr. Leonard:** Oh, I, I think there's a wide range; and it's, it's very hard to know. I'm sure that, that David and other patients, you know, when they were diagnosed and had the treatment discussed with them heard that a lot of things could happen that would be unpleasant and sometimes that happens and sometimes it doesn't happen. So certainly people who are older, people who are in less fit shape, meaning, you know, patients who are elderly patients who are not very mobile, who are sick, who have lots of other medical problems, in general, are going to have a more challenging time with treatment than people who are younger and fitter and going to work every day and doing just fine.

That being said, there are exceptions in both directions, and it's not always easy to predict. And sometimes you can see a patient and think it's going to go very smoothly



and others, and get surprised; and other people you think, well gee, it's going to be a challenge getting them through this, and they do just fine. So, you know, I, I would say that, that the patients shouldn't, should be prepared for side effects; and the treatment team will do a, all their best efforts to minimize those side effects. And you need to be careful, but I would not assume that it's going to be the worst necessarily and, you know, sometimes we're plea-, pleasantly surprised and things can go quite smoothly.

**Lizette:** And, David, were you anticipating having a lot of side effects and were you surprised that you really didn't experience.

**David:** When, we first started talking about the, the treatment plan, all possible side effects were put in; so your mind immediately goes to that's what's going happen to me, the worst case scenario is what's going to happen. At least you start preparing for that. And so whatever level that you get throughout the process, at least you're prepared for the worst. And side effects were, you know in my case, I won't say I didn't have any, but mine were very manageable and tended to be more temporary, more than what would be considered more long term.

So, you know, when you're going through, you never know what your body is going to react to this and what you're going to do. The, when I first took my first round of chemotherapy, I actually had, developed a bit of a reaction, allergic reaction to it as, a couple hours after the treatment was over which, again, it was temporary, a couple hours that it lasted. But just a very scary time because then you think, well, if that happened on the first round, what's going to happen on the next and the following? So it gets you to a point where you're like trying to imagine what all the different scenarios you are but just hoping for the best and preparing for the worst is generally I think what, what most people tend to go through.

**Alicia:** Right. And as new drugs come out in regards to controlling side effects or just new and emerging treatments, doctor, we actually launched a new video on our website about a hopeful clinical trial called CAR T-cell therapy and its role in treating cancers including leukemia, lymphoma, and myeloma. And so what do you think is the most exciting emerging therapy for diffuse large B-cell lymphoma?

**Dr. Leonard:** Well, I think the, the most important thing is that is before we get to CAR T-cells, that the vast majority of people with diffuse large B-cell lymphoma aren't going to get and don't need a CAR T-cell or other therapies. The standard therapy for most patients with diffuse large B-cell lymphoma is a regimen of chemotherapy called CHOP and a drug called rituximab or Rituxan, which is a monoclonal antibody or an immune protein treatment; and that cures about 70 to 80% of people across the board, so that is a good and very effective treatment, and that's for diffuse large B-cell lymphoma, the treatment that the vast majority of people are going to get.

So I think it's important that we start there for the audience so that they know a little bit about that, and that's typically an outpatient treatment that is given over every three weeks for about four months, and the principal side effects include fatigue, hair loss, some nausea, low blood counts, risk of infections being the most common thing; but, again, most people feel, I typically say, 70 to 80% of their normal selves, sometimes better; and many people are able to work and be active and do many of their normal things, albeit with some, some of the side effects that can be serious for some people, but for most people are pretty manageable.

So that's the standard therapy for most people. There are some twists on R-CHOP that adjusts the drugs a little bit in different ways—give them in the hospital, do different things for certain scenarios of diffuse large B-cell lymphoma. We use a, another regimen called dose-adjusted R-EPOCH, which is a twist on R-CHOP, and there are a few other variations that are used in other situations that are less common but may be applicable to some people.

If patients with diffuse large B-cell lymphoma go through their treatment, they're in remission, and their disease doesn't come back, then often they're cured, and they're done and they're in follow-up. If patients' relapse, most patients get treated with more chemotherapy, different chemotherapy drugs, usually stronger chemotherapy approaches; and in many cases, cases, patients who relapse are treated with something called high-dose chemotherapy and autologous or from oneself stem cell rescue.

So the standard therapy for many patients who relapse are, are, are using more chemotherapy with something called a stem cell transplant, and that's a more intensive way of treating the lymphoma. But that can also treat and cure many patients with large cell lymphoma, diffuse large B-cell lymphoma.

If the patient can't get those therapies for various reasons, or if those therapies are not effective, or if the treatment comes back after those, then that is typically a more challenging situation, and many patients participate in clinical trials. Many patients get treated with additional chemotherapy drugs. There are several other drugs that are useful in diffuse large B-cell lymphoma that's come back after several times. There are drugs that are in various clinical trials or have some data, even if they're not kind of standardly used, a drug called lenalidomide or Revlimid, a drug called ibrutinib or Imbruvica. These are drugs that are used for some patients with some subtypes of diffuse large B-cell lymphoma.

There are other drugs in clinical trials, and as you mentioned, one category of treatment that is also in clinical trials at this point in time in diffuse large B-cell lymphoma is called CAR T-cells, and that is a type of treatment that collects from the blood of patients' own immune T-cells, takes them to the laboratory, and essentially engineers them to be more effective at fighting lymphoma cells, infuses them back into

the patient like a fancy blood transfusion, and then those T-cells set up shop and go after the lymphoma.

This is an exciting form of treatment that is in clinical trials, so it's not FDA-approved and not standard, but there are a variety of clinical trials out there for certain types of leukemia and lymphoma, including diffuse large B-cell lymphoma. This is a treatment that is not given as an initial treatment and at this point is primarily being studied in patients where most of the standard treatments haven't worked, and patients are getting this as part of a clinical trial to see how well it works and to see if it can help individual patients. And, you know, we will see how the data show.

There are clearly patients who have benefited from this and had very important remissions when the disease has not been effectively treated with other standard therapies, but how this compares to other treatments and where it will be used ultimately depends on how the clinical trials go and where all that goes in the future, so it'll be a very interesting time. I think this, CAR T-cells, as well as other treatments in clinical trials, are important new treatments that hopefully will benefit patients with diffuse large B-cell lymphoma and other lymphomas in the future.

**Lizette:** So, you said that there's a lot of potential for cure with initial treatments. Do you find that patients will come in and, and ask you about clinical trials at all? Do you think patients know about clinical trials, that they exist?

**Dr. Leonard:** Well, I think that, so first of all, I, I think it's important for patients to understand what the goals of therapy are, meaning we treat any patient with any medical problem, whether it's lymphoma or high blood pressure or anything else. We treat patients either to cure their disease, to make it go away, to make them live longer. Meaning, you know, we may not cure diabetes, for example, but we try to make people, help people to live longer with their diabetes or to feel better. Meaning if you've got a bad, bad knee, we don't want your knee to hurt. If you've got a stomachache, we want to make that feel better.

So those are the three reasons we treat any disease, and it's important that cancer patients and lymphoma patients understand for their type of lymphoma what goal is realistic? Is this a type of lymphoma that we can cure, is this a type of lymphoma that we cannot get rid of, cannot cure but hope to make you live longer and help you to live longer? Or is this a type of lymphoma that, that our goal of treatment is a little bit lower bar, meaning we're mostly trying to relieve symptoms and help you to feel better?

So, in diffuse large B-cell lymphoma, it, that, when we have newly diagnosed patients, our goal is typically to cure the patient. It's important for the patient to know that so they know why they're doing the treatment, how likely that is to happen. So with every new patient, I tell them you have a diffuse large B-cell lymphoma. If it is curable, I

say, and it usually is in that subtype, “Yes, it is curable. Our goal is to cure this, and the chances of curing it are estimated to be,” whatever percent we estimate it to be.

And in some cases we have clinical trials where we’re offering new treatments that have the possibility, not the proof, but the possibility to add a new treatment that in some cases we hope will improve the chances of cure or, in other cases, perhaps will make the treatment a little bit easier for the patient so that maybe the chance of cure or the chance of effective treatment may not be changed that much, but that if the treatment is easier, that could offer value to a patient as well. So clinical trials are something that every patient who needs treatment should ask about because there may be some clinical trials applicable for any individual patient, regardless of their situation at centers where they have clinical trials and a lot of opportunity for, for patients.

**Alicia:** And, David, with your treatment journey and with the discussions that you’ve had with your healthcare team, is clinical trial something that you knew about and then later asked them about or was it something that they brought to the table?

**David:** We were fortunate to be brought to that, they were brought to us as an option; and let me say too that that the Leukemia & Lymphoma Society has a fantastic resource on their page about clinical trials that’s made it so much easier to research, to find out what is available out there.

**Alicia:** Yes, clinical trials are a very important resource for any blood cancer patient, and we encourage anyone on this podcast to listen all the way to the end of the episode where we will provide the contact information for the LLS Information Specialists. LLS Information Specialists provide much support and many resources to many blood cancer patients, one of those resources being a personalized clinical trial search. So, again, we encourage you to listen all the way to the end to gather that information. Now let’s jump back into the episode.

**David:** We were brought a lot of those as, as a treatment option at the very beginning; and we were always known or always let known what types of clinical trials are out there. If I might qualify for one of those, is that something that we should consider; and that was always brought up as a possibility for a treatment plan for me.

**Alicia:** Great.

**David:** So, yes, the oncologist that we went to and that we saw were not only well up to date with everything but were often leading and were a lot of times being the primary catechist behind the treatment.

**Alicia:** Right. So I know this might sound like a cliché question, David, but when the diagnosis comes into your life and now this becomes, what they say, the new normal,

what did you learn about yourself, you know, from this experience or the strength that you found that you had? What were the major lessons that you learned since being diagnosed with diffuse large B-cell lymphoma?

**David:** I would say on the most part, I'm still kind of waiting for that life lesson to come. I'm not exactly sure what, you know, what and the why, but I did find out a lot about myself through this process and that this challenge is a challenge that I took when I would be let's say running a long distance race. And what worked best for me in this process was to kind of take it on a mile-by-mile basis. So, on a half-marathon that I had run about six months before diagnosis, I had always thought about the next mile or the current mile and not the, the 10th mile, so to speak. So for me, the process of getting through this treatment plan was mainly focused on what have I got now, what treatments have I, are going on now, what, if any, side effects am I feeling at the current time and not worrying about what the next round is going to bring, or the next round after that, or the next round after that. So, for me, it was much more of how I approach just about any challenges is take what's in front of me, be able to control what I can control, and worry less about what I can't.

**Alicia:** Which is so important for everyone to hear. Doctor, do you have a different perspective when it comes to now being on the other side of the diagnosis? Is there anything that you think that they should know about for this point of their life?

**Dr. Leonard:** Well, I think, you know, what bothers me is when patients don't understand what they need to understand, when they're not informed on what they need to know. So I think, you know, certain scenarios, it's, it's easy and, and practitioners are very good at giving the patient all the details about what to expect out of their disease, what their treatment options are, and what the milestones are in going through treatment and assessing the response and the follow-up. But, you know, others are less good at it for a variety of different reasons; and I think it's important to, I, I would hate, and I do hate when patients, you know, are more worried than they need to be. On the other hand, I don't want them to, to be less worried, to a degree, than they need to be, meaning if, the if, if they don't understand the severity of their situation and are not doing, getting the right treatment or the support that they need, then, then they need to understand.

So I think it's very important for patients to have as much information as they can from reputable sources, not just from all over the Internet but from places like LLS and other organizations, from their physician, nurses, treatment team at their treatment center, really good information on what their diagnosis is, what the expectations are for treatment, what the options are as far as clinical trials, and then, you know, keeping through the treatment course, keeping everybody informed so that everyone is in the loop and knows what's going on so that the appropriate care can be delivered so that outcomes have the best chance to be as favorable as possible for the patient.

**Lizette:** And I want to thank you for saying that because it's very important to hear from someone like you, Dr. Leonard; you're a key opinion leader, to really let patients know that to please communicate with your doctor, to please communicate with your treatment team, and that's the only way to really understand the diagnosis, the treatments, and all the potential treatments that are out there.

We often get calls from patients and caregivers asking us questions that we, frankly, were amazed did not ask their treatment team; and we let them know that their treatment team wants to hear this information from them, and they go back and they do talk to their nurse or social worker, their physician. And they're so happy they did because they've gotten the information and the information is individualized to them, so it's really important to hear that patients should be speaking openly with their treatment team.

David, I hope you've had that experience that you were able to freely speak with your treatment team to get all the information possible so you knew exactly what was potentially going to happen in your journey.

**David:** Right and I was given a lot of information; but I think what a key thing from a patient perspective is, you're going to hear a lot of things that will tell you about what they're going to do to rid the cancer now. And if it's definitely going to be treatable, that, you know, you're going to hear about the short-term effects of, of what's going to happen.

But what I don't think a lot of people are hearing or what people should be asking about is also about the long-term effects of the treatment. You know, is, what, what's going to happen, not six months from now, but six years from now; and, ultimately, everybody wants to get to that point anyway, and it's a problem. Everybody who initially comes in with a diagnosis wants to have those things, but I think those are good things to ask for a patient, is to ask what, you know, what are the long-term effects of going through this type of treatment? What are the long-term effects of a stem cell transplant? What are the. 20 years down the road, what, what can we know or what do we know now of the effects of this particular treatment plan? So, I would encourage any patient to, to ask not only about the short-term but also about the long-term types of things that they could be looking at down the road.

**Alicia:** Doctor, we didn't really touch upon that in detail in regards to side effects of the disease. What are possible long-term and late effects of treatment?

**Dr. Leonard:** Well it really depends on the nature of the treatment, but generally speaking, patients diagnosed with, with diffuse large cell lymphoma or really any lymphoma should certainly raise issues with their doctor as to what the specific long-term side effects of, of their treatment can be. Certainly, after treatment for a period of time, there can be, you know, the immune system can be suppressed. There may



be risk of an infection. There may be fatigue. Certain treatments can affect the, the lungs, the heart, liver side effects, kidney side effects occasionally. Again, these tend to be much less common, but for certain drugs on occasion that can be an issue.

What we often worry about, or at least think about. I shouldn't say we should often worry about them, but we should think about for certain treatments there can be risk of fertility problems. So if a patient is planning on having a family or at least considering it, sometimes it's a young person who's not sure, certainly at least consider options with regard to fertility preservation. Certain treatments have no effect on fertility, but other treatments may affect a woman's a, ability to become pregnant in the future, or a man's ability to father child in the future. So, certainly asking one's doctor about those issues in, in relation to the treatment that's being planned. If that's even a remote possibility, and for many patients that's a, you know, an important consideration. They know that. Certainly, getting a consultation with a specialist in fertility or doing, doing sperm banking is an important step to take the time to become informed because those are decisions that often have to be made relatively quickly in the tur-, in the time when a patient has a lot of other things going on with respect to their lymphoma.

And then the other thing is that, you know, we are always attentive to longer-term side effects. Again, heart disease, thyroid disease in some treatments, and risks of other cancers like a leukemia, lung cancer, or other cancers that can be associated with radiation or with certain chemotherapy drugs. So, for some people, these are very minor concerns based on their situation, where they are in their life, their age, their other medical problems, and the nature of their treatment. And for other people, these are very big issues that can be very important based on their individual treatment and where they are in their lives.

So, the key thing is not to generalize one way or another, but to really be very direct with your doctor and your treatment team, saying what are my risks of long-term side effects? What can I do to prevent them? What can I do to deal with them in advance so that the chance of them being an issue is minimized for the future? So that is an important issue that people should think about, and it's hard because in the middle of getting this diagnosis and you want to get cured and you're in a hurry to get treated, having these conversations and plans about what could happen many years from now or what is not a priority for you in your life right now when it comes to fertility, in some cases, but may be a priority for you in 5 or 10 or 20 years is something that you have to think about and plan for even if it's not at the top of your priority list on that given day.

And I think it's a responsibility of the treatment team to say, "Hey, you know, I know you're not worried about pregnancy right now. That's not a big issue for you right now, but trust me, it may be in the future. So, let's make sure that we do everything we can now to plan for that, based on trying to keep you having all the options that you may



want in the future and, and having the best outcome not only now but 20 or 30 or 50 years from now.”

**Alicia:** So important.

Thank you so much to both of you for your time with us today. Dr. Leonard, thank you for the information that you shared with us and for what you do for the many patients that you serve. Thank you, David, for sharing your story and letting others know that they're not alone and we're so pleased to hear that you're doing so well. I'm sure our audience appreciates hearing from you as much as we do, so we just want to thank you so much for joining us, and we wish you the most success.

**Lizette:** We'd also like to thank Kite Pharmaceuticals for their support of this episode.