

The Bloodline with Blood Cancer United Podcast

A podcast for patients and caregivers

Episode: ‘Chronic Lymphocytic Leukemia (CLL): Managing Treatment and Finding Balance’

Description:

Some people with chronic lymphocytic leukemia (CLL) may feel well day to day, but that doesn't mean life stays the same. In this episode, we hear from Annette Holloway, a clinical psychologist living with CLL, as she shares how her diagnosis, treatment decisions, and side effects have shaped her daily life. Also joining us is Elise Curry, RN, OCN, a Clinical Trial Nurse Navigator at Blood Cancer United's Clinical Trial Support Center, who helps break down treatment options, side effects, and the importance of communication with your care team.

Transcript:

Elissa: Welcome to *The Bloodline* with Blood Cancer United. I'm Elissa. Thank you so much for joining us on this episode. Today, we are discussing chronic lymphocytic leukemia or CLL. Our first guest is Annette Holloway, a clinical psychologist who was diagnosed with chronic lymphocytic leukemia or CLL in February of 2021, not long after visiting her doctor with symptoms.

Since her diagnosis, she has switched oncologists and continued adjusting her medications. Then, in late 2023, while managing her CLL, she was diagnosed with MGUS or monoclonal gammopathy of undetermined significance.

Blood Cancer United

Later in the episode, we will be speaking to Elise Curry, a Clinical Trial Nurse Navigator from Blood Cancer United's Clinical Trial Support Center to discuss and expand on Annette's experience. Welcome Annette.

Annette Holloway: Hi, Elissa.

Elissa: Well, thank you for being here with us. So, let's start with your diagnosis of chronic lymphocytic leukemia or CLL. What were the symptoms that brought you into the doctor, and how did you end up getting diagnosed?

Annette: Well, I think the biggest one was I was not getting rest from sleep, no matter how much I slept. I felt exhausted. I felt weak. After the fact, I realized there were other symptoms, as well, but the main one was the rest issue. And honestly, I went to the doctor to do a sleep study because I thought I had sleep apnea.

Elissa: Okay.

Annette: But I will say this. Between the time that I made the appointment with my primary care, and then I saw him, my symptoms did get significantly worse. So, I think I had passed some kind of moment in terms of my energy and some other little symptoms; and then, I caught it at the moment when it needed treatment.

Elissa: Okay. So, when you went into your primary care then, did they catch it on the blood test and then refer you over to an oncologist?

Annette: Essentially, what happened was, my primary care person I met with him. He gave me the sleep study referral; and he said, “Let’s do some bloodwork.” And so then, I did the bloodwork a couple days later; and then he said, “Let’s do the bloodwork again.” And then, you know, he said, “Well, you know what, I’m going to talk to a colleague.” And so, there was a series of back and forth, and the bloodwork was repeated several times. And he referred me to the oncologist who did the bone marrow biopsy.

Elissa: So, when you were diagnosed with CLL, what was that conversation with your oncologist about the disease and what to expect? And did they discuss options and medications?

Annette: So, I was very freaked out. I’m not a fly-off-the-handle kind of person, but I was so surprised. The first thing he said that I remember, after saying, “I think this is quite likely,” because I think the conversation wasn’t till after the biopsy. And frankly, I don’t remember exactly who said what when; but I do remember he said, “Don’t look at the statistics online because they are so different from the old days.” And, you know, I didn’t have a very specific idea of what leukemia was. I knew it wasn’t good. I knew it was cancer, but I really didn’t have a lot of preconceived ideas. So, I was like, “Okay, I won’t look at this.” You know, I just didn’t. And he said, “We’re going to start treatment right away.” And he gave me an option of Imbruvica® or a combination therapy.

Blood Cancer United

And I asked for more information because he was willing to give me a couple days; but he wanted to start treatment right away, which also kind of was like, “Whoa, really.” So, I asked for more information about the medications. I just remember feeling like I kind of had hit a wall with him. He did immediately email me some stuff, but it was just to the page for each medication that the pharmaceutical company put out.

Elissa: Okay.

Annette: So, he didn’t have any referrals to the CLL Society, to what was then The LLS (The Leukemia & Lymphoma Society). That was a big reason why I ended up switching oncologists because he was a very smart, very knowledgeable guy, but he just didn’t seem to have that understanding of how to deal with patients. He was a great guy. It wasn’t a good match.

I remember asking him what would you suggest; and he suggested the Imbruvica, and I said, “Oh, okay. Well, let me think about it,” and I got back to him and that’s what I ended up doing. The important piece of information that I wish he had mentioned was, I knew that the Imbruvica, you’d be on it until it wasn’t working anymore. It’s not like, you do a course of treatment and then it ends.

Elissa: Right.

Blood Cancer United

Annette: But what I didn't know was that with the other treatment, there was a chance of some amount of time of feeling cured. I know there isn't really a cure, so I don't want to mislead people.

Elissa: Right.

Annette: But minimal residual disease (MRD), when you test your blood after this other treatment; and when I really realized what that would feel like, I really wish I'd gotten more information about that. But-

Elissa: Yeah.

Annette: -I asked for his advice. He gave me his best advice; and, yeah, and I tried to take it in.

Elissa: Yeah. First, going back to the Googling, we hear that quite a lot from patients; and myself as an AML patient, acute myeloid leukemia, I got the same advice. "Do not Google it." Those statistics might not be fully accurate. They also might not be relevant to you because everybody's different, even with the same cancers. And so, I'm glad that they said that to you. But then, also, communication is so important. And we talk a lot on the podcast about shared decision-making, particularly with chronic cancers like CLL, that it is important to understand the risks and benefits of each of the medications and side effects that may come along and like you said, with the other one that may give you a chance to be MRD-negative and be able to maybe

Blood Cancer United

go into watch-and-wait period where you aren't on any medications at the time until you progress again.

And so, I'm glad that you realized that there was a communication issue and moved onto a different oncologist that maybe had more of a communication style that you were comfortable with.

Now, I realize that I should explain to our listeners who might not know what minimal or measurable residual disease is. And so normally you get a biopsy to test to see if there's cancer cells or leukemia cells; and this is much deeper testing to go further than that to see if maybe there is one in a million versus one in a thousand cells and, so it is a much deeper testing to see if there are any cancer cells left.

So, could you tell us more about the medications because I know at some point you also switch medications. I believe you started with Imbruvica, which is also ibrutinib, the generic name for patients who might know it better with that. And that's a BTK (bruton kinase) inhibitor, correct?

Annette: Yes. Yes, it is. It's a BTK inhibitor, and I am on a different one now, zanubrutinib, which is, actually more of a second-generation BTK compared to ibrutinib. It was done because Kaiser's formulary changed (formulary: a continually updated list of prescription medications covered by a health insurance plan). They

Blood Cancer United

both worked really well for me. I think there's fewer nonsignificant side effects on the zanubrutinib for me. I'm sure that's an individual response, but-

Elissa: We know that the cost of care can create real stress for patients and their loved ones during and after cancer treatment. Before we continue, we want to highlight a resource that may be helpful for our listeners.

So, since there are different options available, right before you moved to zanubrutinib and the ibrutinib had been taken off of the formulary, was there another discussion with your doctor about options available to you before you picked the zanubrutinib?

Annette: I had just started seeing him, and I wasn't focused on that. I don't remember if he asked about other things. We might have discussed it. At a later time, I did bring up this issue of could I have the combination of the two infusions as opposed to the daily pill? And he said yes. If you want to switch, you absolutely can switch. And we went through the pros and cons; and basically, in the end, I thought the devil you know versus the devil you don't. Because there are side effects and, at that point, I was used to just taking the pill and, yeah, so, I ended up not switching. But he was very open to it.

Elissa: Right, yeah. I'm so glad that you did go over some options, and you decided what you felt was right for you at this time. And so, in the future, you have other options available.

Blood Cancer United

So, you had told me outside of this podcast that you had been adjusting the dosage of the zanubrutinib. Can you discuss that, the reasoning behind it? Was it because of side effects, or what were the conversations happening with your doctor regarding the adjustments?

Annette: So, we adjusted the zanubrutinib. I don't remember why I asked about it, if it was possible. But he said, "Sure, no big deal. Let's cut it in half," and we tried that, and then three months later we went up to 75% of the regular dose. So, it was something that I initiated. He totally worked with me. And so, and that's where I've now been for two years.

Elissa: Good. I'm glad, again, that you've had that good communication with your doctor, that you're asking questions and, trying to find just the right thing for you. So, that is great that you've been able to adjust the dosage and that has seemed to work for you for at least a couple years.

Annette: One thing I really appreciate about my oncologist is if I see something, and usually it's like a medical journal article, I have access to them because I'm a psychologist and because, of course, I'm very interested in finding out about what's happening, I can send him the link and ask him my question, and he always responds. And I really appreciate having someone who can welcome that, who can say, if he's seen it, if he's not aware of it, and take my questions seriously and get back to me. So, having somebody like that on your team is awesome.

Blood Cancer United

Elissa: So, you've mentioned side effects several times. What side effects have you had from both of these medications?

Annette: You know, it's funny. The one that I first really noticed was my hair got curly. There were changes in my nails and hair. And, again, this was, with my first oncologist; and he said, "Well, that's not a side effect." He was very by the book. Of course, if you go to the patient chat boards or you look into it, a lot of patients have these side effects. So, why they're not on the official list, I don't know. Maybe they didn't think it was important because. I just was, like, "Ooh, I kind of like that," you know, once I got used to it.

I still have some of those changes. The one that affects me the most at this point is, unfortunately, diarrhea. And that is from the medication. And so, that's been kind of a journey figuring out how to handle that. Because when I was diagnosed, it was COVID. It was an issue, for sure, but you were just home all the time. So, the bathroom was always there.

Elissa: Right, yeah.

Annette: Yeah. So, it wasn't as big as a deal as I think it would have been if I had been having my normal life, what was my normal life pre-COVID. Now, I know how to handle it, control it, so it's unpleasant sometimes but it's not a social problem.

Elissa: Yeah.

Blood Cancer United

Annette: And it's, obviously, not life-threatening in any way or painful. One can have a lot worse symptoms, but I would say that's the main one. I do bruise easily, and some of these, I'm not sure if it's the CLL or the medication or the combination. So, I bruise easily, and I heal very slowly.

Yeah. Another thing that has happened; and again, I don't know if this is the medication or the CLL. Any kind of skin issue, whether it's a bite, mosquito bite, spider bite, small cut or something, it heals really slowly. And I don't know what this is from. I think it has to be the CLL or the medication because of the timing. I feel like I have this phlegm always in my throat and it's just a higher level. And I don't know any other reason why it would be there. It could be a general sign of aging; but, again, the timing was pretty suspicious to me.

Elissa: Yeah.

Annette: So, it's a random one. I haven't even looked it up. I've tried to talk to my doctors about it. Everybody's like, "No, I don't think that has anything to do with anything." And so, I don't know. All I know is it's there and it wasn't before.

Again, minor changes. These little things to me are more the daily reminder you have cancer, you have cancer, you have cancer. And now I'm used to it more. Initially, that was upsetting. To me CLL is a very strange disease because once I was on the

Blood Cancer United

medication and I felt better, and that took a number of months. Like right now, I feel pretty much like myself. I think I'm a little more fatigued, but who knows. Those things are hard to quantify why that is. Again, age could be part of it.

I basically feel fine; but I have this serious disease, and I have a permanently compromised immune system, as far as I know. That's always going to be there. And that is very odd because, when I was first diagnosed, people afterwards said, "Annette, you look so pale". People were too polite to say anything. I feel like some of them noticed something was wrong before I did. But now I don't feel sick, which is wonderful.

Elissa: Yes.

Annette: The BTK inhibitors are awesome, if you can tolerate them. But I still have to be really careful about infection. And I think because it's so invisible, other people forget it too. My family forgets it, which drives me crazy. Not my husband or my child. They're awesome. Like extended family, and that is very upsetting that they can't seem to- it's such a central part of my life.

Elissa: Yeah.

Annette: Managing infection risk. I don't go to indoor restaurants anymore. I haven't since I was diagnosed. I'll go to an outdoor restaurant, and I'm looser now than I was initially. I mean as you sort of realize what you can and can't do.

Blood Cancer United

Elissa: Yeah.

Annette: But it's odd to have a disease where you basically feel fine, but you're totally not fine.

Elissa: How does your family end up dealing with you being immunocompromised? Is that something that is top of mind for them to where they're protecting themselves outside of the home to not bring things back to you, or how does that work with your family?

Annette: Yeah. Well, my son is an adult, and he doesn't live with us anymore. So, when he comes over, if he comes in, he wears a mask until he tests, which I'm now comfortable with. Before, let's say he'd been out the night before; and I would be like, "Ooh, I don't know. Let's sit outside," you know?

Elissa: Yeah.

Annette: But, he's very aware of it and very careful and so is his girlfriend. My husband is awesome. When he goes out, say he goes into a store, he always wears the mask because I always do too inside. And it's a pain, you know.

But I really appreciate my husband's thoughtfulness and consideration and follow-through on protecting himself, which means protecting me. Yeah. He's great with it.

You can't say too much about the people who love you who are helping you stay well.

Blood Cancer United

Elissa: Yes, yes, that is very important. It's your village, right? It's your village that is making sure that you're protected and that you are safe because, I assume that, with where you are right now that any cold, flu, COVID, anything like that could potentially land you in the hospital because it's difficult to heal from?

Annette: Yes, and it did, actually. I got a little lax. I was visiting New York, where I used to live, and I was visiting friends, and everyone was great. But it was hot, and I got sick of masking everywhere. And so, I got a little lax; and I came home, and I got COVID, which I, of course, gave to my husband. His symptoms were bad for maybe two days. Mine didn't get better, turned into pneumonia, and then I ended up in the hospital for four days.

So, I do have to be careful; and believe me, I've gotten every single COVID vaccination every six months like clockwork and all of that. And, hopefully, it helped a little bit. But I guess my T-cells weren't strong enough. I don't know. It was a difficult experience, I will say.

Elissa: So, being immunocompromised has had an emotional effect on you?

Annette: Emotionally, overall, I will say the biggest effect has been in the winter when it's harder to socialize outside. Now, I live in Northern California near the ocean, so, it's not like snow here. It's rainy, windy, cold, and people don't want to hang out outside and have a sandwich or even a cup of tea, you know. And so that difficulty socializing

Blood Cancer United

has made a big difference. Also, I do not see clients in person anymore. Not since COVID and my diagnosis. So, that professionally has been an adjustment.

I was seeing some people online, even before COVID, so it wasn't like I had never done it. But it's harder to find collegial opportunities with my peers because even if I decide to go to some kind of in-person seminar or training, I'm wearing a mask. I'm trying to sit by an open window or an open door. I'm not eating and drinking around the snack table. There's a certain amount of social isolation that's been hard for me.

Elissa: Yeah. Yeah, it sounds like the social isolation that comes with being immunocompromised and then also the side effects that you brought up that remind you every day that you have cancer have seemed to be somewhat difficult for you.

Annette: Yeah, yeah.

Elissa: Now, before we finish up today, I'd like to touch a little bit on that diagnosis of MGUS. How did you get diagnosed with that, and did they think it was something that was happening with your CLL?

Annette: I actually noticed the anomaly in my blood tests.

Elissa: Oh!

Annette: Another positive thing about Kaiser, is it's easy to track trends of your bloodwork. So, I noticed that some things had been not wildly out of the norm but had

Blood Cancer United

been and were getting worse. And so, I asked my oncologist about it. And he looked at it, and he said, “Oh, wow.” So, I didn’t know what it meant. I had no idea that that would mean another diagnosis. But I just saw the trend and wondered about it.

So, it was a result of the regular blood testing. I happened to be the one to notice the trend, but, of course, I wondered if it had anything to do with CLL. He said it didn’t, and it happened to turn out that a good friend of mine had recently been diagnosed with MGUS, who does not have any kind of blood cancer or any other cancer. So, that was really helpful because he could really confirm that his doctor, too, had said, “You may not have to worry about it. It might not be anything. It’s another thing to watch,” so that really helped. Between hearing my doctor say that, reading about it on your website, on some other websites too, and talking to my friend, I realized it’s a fairly common thing and it doesn’t necessarily mean anything else will happen. And it’s not related to CLL.

Elissa: That is good to know.

Annette: That was all helpful.

Elissa: So, our final question today, on our patient podcast home page, we have a quote that says, “After diagnosis comes hope.” What would you say to newly diagnosed patients and their loved ones to give them hope after a diagnosis of CLL?

Blood Cancer United

Annette: Listen to your doctor, and if you choose to Google, only look at anything that's after 2015. I know the BTK's don't work for everyone, but they work for a lot of people. There are so many choices out there, and there's a lot of new medications always being developed.

So, one of the things I've taken away is that if you're on a certain medication and it starts to not work anymore, there will be another one to try that likely will be helpful.

Elissa: Well, that is great advice, and thank you so much, Annette, for joining us today. And I'm glad we had this discussion of your communication with your doctor all about the medications and side effects and everything so that you're managing this disease very well.

And then, you and I were connected through our Patient Community. You had mentioned, the patient boards that you had been on where you can talk to other patients; and so, we'll have a link for that in the show notes if patients want to join in. So, yes, thank you again, so very much for telling us all about your experience with CLL, and we really appreciate you being here.

Annette: Well, I really appreciate the opportunity to share my story. I hope it's helpful.

Elissa: Thank you, Annette.

Now, we'd like to talk a little more on CLL with our Clinical Trial Nurse Navigator, Elise Curry. Welcome, Elise.

Elise Curry, BA, BSN, RN, OCN: Thank you, nice to be here.

Elissa: Well, thank you for being here with us.

So, we started off our conversation with Annette, hearing that she was given two options for treatment and later switched to a different one. Could you tell us what options are generally available for frontline or first-line treatment of CLL?

Elise: Of course. So, CLL is an area where we have come so far in recent years. We've really gotten away from the traditional chemotherapy days for most patients. We've gotten really good at understanding how the CLL works, and so because of that, we've figured out how to interfere with the way that it grows and proliferates in the body.

So, the way that one of these drugs, class of drugs, the one that Annette received works, the Bruton's tyrosine kinase inhibitors or BTKi's, they're targeted to the mechanism that actually drives the CLL. So, these drugs, in essence, to use a metaphor, cut the phoneline that CLL uses to talk to each other and send and receive signals telling it to grow. So, that works very differently from the traditional chemotherapy that kind of just goes in and big guns, kills everything that's growing quickly.

Blood Cancer United

So, when discussing treatment options, first off, with CLL, it's really important to point out that every patient is unique. Treatment recommendations vary based on the unique features of each person's CLL. Some patients, for example, may not quite meet criteria for treatment yet. Some patients are indicated for careful watching or watch and wait; and that gives some patients a little more treatment-free time.

Now, of the treatments that are now recommended per the guidelines, that a lot of practitioners, most centers use, the NCCN guideline. That stands for National Comprehensive Cancer Network. They recommend two main approaches, one being time-limited combination regimens and then another being continuous BTK inhibitors, of which there's multiple to choose from as we learned from Annette's experience.

So, for the time-limited treatments, that's generally indicated for about a year. It's a combination, usually BTK inhibitor based with a BCL2 inhibitor, of which one of those drugs is a drug called venetoclax. And it may or may not be combined with a monoclonal antibody, which is an IV medicine. Gazyva[®] is a name for, for one of those. Or it could be the BCL2 inhibitor-venetoclax-based therapies with just the monoclonal antibody.

And then, after the predetermined treatment duration has been met, patients are observed carefully after completion of therapy. So, that's one avenue. Another is continuous treatment that Annette was recommended. So, that's usually BTK-inhibitor based. It may or may not also include that monoclonal antibody, the Gazyva.

And that is just continued until patient's CLL returns or if they're not tolerating the medicine, at which point they can switch. Sometimes, it could even be to another BTK inhibitor such as Annette experienced because there are multiple drugs in that class.

Sometimes, it's nice to have options; but it's understandable though that some patients may struggle when given choices. I know I'm not a great decision-maker. I don't like having too many options.

So, if you haven't given options with treatment and depending on the urgency of needing to start treatment, you may want to talk with someone else, someone who, perhaps, has experienced this treatment. You know, one of the treatment options that you've been offered. Blood Cancer United, of course, has wonderful resources to do this. Connecting with other patients, our [Patti Robinson Kaufmann] First Connection[®] Program, one of my absolute favorites. I recommend it to all my patients I talk to. You're matched with a peer mentor who you can speak to and get that perspective, that first-hand, been-through-it perspective. And then, of course, our team here in the Clinical Trial Support Center (CTSC). We work one on one with patients and can help navigate questions just like this.

Elissa: It's good to know that they do have somewhere else to go because it can seem overwhelming, right, with so many choices, which is great. It is great that there are so many choices available for CLL treatment, so in case one maybe doesn't work, there's

other options available for you. Thank you for giving us that overview of all the different options available for patients.

Elise: Of course, yeah.

Elissa: So, next we discussed side effects with Annette that she had as a result of the BTK inhibitor. What side effects are common, and also what can patients do if they have a side effect that isn't very common – like she mentioned with her hair, nails, and phlegm?

Elise: Yeah, it's important to know that most BTK inhibitors are generally well-tolerated and side effects manageable. So, that's sort of the nice, wonderful thing about this new class of drugs is that it's not those traditional chemotherapy effects that a lot of patients anticipate when they hear, "Oh, I have cancer. I have to have treatment." So, generally speaking.

Now, some of the most common, in addition to the ones Annette experienced, like the diarrhea and the bruising or bleeding, are infections. Achy joints or muscles, that happens sometimes. Fatigue or headache. Some of the less common ones or maybe skin issues sometimes, cardiac abnormalities. There is one particular BTK inhibitor that can cause heart rhythm changes. So, but it's less common in some of the newer generation drugs, such as the zanubrutinib.

Most important thing to remember when it comes to side effects is that no symptom is too small to discuss with your care team. Most centers do a great job of educating patients. They give you handouts, they tell you what to expect from the most commonly expected side effects like the ones that I mentioned. You know, and then doctors can also speak personally from what they've seen in their practice. The side effects they've seen in their own patients. But, generally speaking, when we give you the list of side effects, those come from information collected in clinical trials. And we know that clinical trials are not always reflective of every demographic group, and that's for a plethora of reasons. That's a whole 'nother talk, but it's not to say that a side effect you're experiencing, such as kind of the unique ones Annette experienced, it's not definitively or is related to the medication. It just, may be that we haven't seen that before. We haven't seen the curly hair happen or the excess phlegm.

You should never ignore a side effect. You should always bring it up, and then, that open communication with your care team is key in that.

Elissa: Yes, that is really good advice to always bring it up. Even if it seems really small, it's something that they can bring up and hopefully get managed, as well, because there's a plethora of things that doctors can do, whether it's medications or other advice that they can give to patients to help manage those side effects.

So, let's discuss the emotional impact that patients like Annette can experience. One of the main things she spoke about was the difficulty with the immunocompromised.

This changed how she manages her life and how she interacts with family and friends as well as her clients at work. She also brought up that with being immunocompromised and having those side effects of the medication, she has a continual reminder that she has cancer. What can patients do to manage the emotional impact of CLL?

Elise: This is such an important thing to talk about, and it's one that often goes under addressed. So, first off, to address the infection, risk concern, it's important to know that many preventative measures can be taken to help give the immune system a hand, so to speak. Yes, you have cancer. Yes, that affects your immune system. Yes, the treatment affects your immune system. But that's not to say that we don't have things in the armamentarium to help counteract that.

So, doctors will recommend things like vaccinations, staying up to date on your vaccinations, taking preventative or, the medical term, prophylactic medications to kind of help supplement the weakened immune system. We can also help it out by replacing a type of immune cell-making protein called immunoglobulins, and that can be given through an IV. That's particularly applicable in CLL patients.

So, it's important to talk with your care team, understand what degree of precautions you need to take and need to be put into place, and then what measures need to be taken. So, that said, when you take these immunosuppressing medicines, especially ones that have to be taken indefinitely, it's absolutely understandable that you can

Blood Cancer United

feel as though you need to isolate yourself, you know, that's the only way to help you stay well is if you stay away from the rest of the world.

And then another emotional aspect, as you mentioned, is that CLL patients who continue on treatment indefinitely, you know, it's taking daily medicine and dealing with those daily side effects as that constant reminder.

So, it's especially hard at first. I like to encourage patients to give themselves some time, give themselves some grace, especially in the beginning to adjust to your new normal. Right, so this may look like going to the grocery store at 8 AM on a weekday instead of going at 3 PM on a Sunday when the stores are packed, asking anyone in the household if anyone in the household has been sick before having visitors over or going to visit with someone else. Modifying your diet. Making sure it includes lots of fruits and vegetables in order to support a healthy immune system. Again, something needs to be discussed closely with your doctor because some patients require more or less restrictions where that's concerned.

Finally, to actually answer your question, it's important for patients to know where they can turn when they're feeling alone or isolated or low. And, again, Blood Cancer United has so very many resources for patients that provide an outlet when you're experiencing these things. You don't need to go it alone. You don't need to feel like you're the only one experiencing these things or has ever experienced these things.

Blood Cancer United

So, as I mentioned before, First Connection's my favorite. Any patient that I've recommended for it and followed up afterwards and go, "Man, that was so awesome." Getting to talk to someone who got zanubrutinib, and, "After a week, I had this terrible nausea that I couldn't make go away. And they told me how they had some medicine they took every morning or they had little meals throughout the day. And it really just made me feel like I was not alone in this, that someone else was experiencing it." So, can't say enough about, about the First Connection program and speaking with a peer.

So many other things. Family caregiver support groups, online chats, our patient Community, our Blood Cancer United Community is another really wonderful resource, sort of like a social media that's monitored by our Blood Cancer United staff, in-person support groups, things like that.

There's other nonprofits that also have really wonderful resources. CLL Society is fantastic. Can't say enough about them. They have really similar and very well-done resources, similar to us here in Blood Cancer United. And again, if there's anything weighing on you about your diagnosis or plan of care or you don't know how to approach your care team about it or you want to learn more about a possible side effect, you can always call our Information Resource Center, call our Clinical Trial Support Center, speak with one of us. We don't give medical advice, but we're always

Blood Cancer United

happy to lend a listening ear and kind of help sit in that moment with you and talk through how to approach these things with your care team.

Elissa: Yeah, it's good those resources are available. I especially like the patient community. That is how we were connected to Annette in the first place.

Elise: Oh, wow.

Elissa: And, and I know that she really benefitted from getting on the patient boards when she was asking about the side effects. Was like, "Who else has had these because I feel like I'm all alone?"

Elise: Oh, wow.

Elissa: And she found out that a lot of other patients were having the same side effects. And so, I think she didn't feel quite so alone in this; and so, it is really good to connect with other people who are experiencing the same thing.

Elise: How wonderful, yeah. Yeah, for sure.

Elissa: Yeah. So, one major theme that was brought up throughout the entire discussion with Annette was shared decision-making or having good communication with the treatment team – asking questions and understanding your disease and treatment options. Why is shared decision-making important, especially with a chronic cancer like CLL?

Blood Cancer United

Elise: Yeah, it's so important. And I think Annette did a great job of educating herself and communicating her needs with her care team. She pointed out that she felt as though she didn't have appropriate expectations set, wasn't really given the time or resources to truly understand the treatment and the full scope of what she was looking at as in like treatment indefinitely, you know.

So, she empowered herself by seeking another opinion. And when it comes to second opinions, many patients are afraid to consider this because they presume their doctor won't support them in it or will be hurting their doctor's feelings by asking for another opinion on their care. And honestly, many patients are surprised to hear their doctors are often in full support of their patients getting a second opinion because, in the end, your doctor wants what's best for you. So, it's never wrong to do this; and when patients come to us in the Clinical Trial Support Center, we talk them through things exactly like this. Our goal is for them to be the most informed and the most empowered they can be. And sometimes that does mean seeking another opinion or a better match with your doctor. And this is what we mean by shared, decision-making. It's a joint effort, it's a partnership. You have to be an informed partner to be a partner in your care.

And so, this requires good communication. A common theme we hear from patients here in the CTSC is that they just aren't sure how to develop better communication with their care teams. They feel like, "My doctor's just too busy for my questions, and

Blood Cancer United

they have way sicker patients than me. And I don't want to take up my time with this silly little, 'Oh, I noticed something new about my nails.'" You know?

We here at Blood Cancer United, offer some really wonderful practical question guides on our website that really help prompt questions and communication with the care team. Questions on topics such as side effects, treatment options, how to interpret tests. And of course, our team of nurse navigators, that's something we do often is help patients formulate lists of, okay, I'm seeing my doctor tomorrow. Just what do I need to ask because I'm so confused. I don't even know where to start, and so we'll kind of sit with them in that and go through, "Okay, this is what you should ask about this. This is what you should ask about that."

And then another point that I mentioned above that is paramount is to educate yourself. I realize everyone's different. Sometimes more info is not always better. You should really seek out information according to your personal learning style. That said, there are so many ways you can educate yourself; and it starts with finding information in the right places, right? You know, the Internet's a wild place, and patients have to be careful of avoiding Dr. Google. Of course, Blood Cancer United has wonderful educational materials and webcasts, podcasts, written materials, such as booklets and fact sheets. And I know I mentioned the CLL Society that has wonderful and well-done resources, as well. Otherwise, we typically advise patients to look for the .orgs or the .gov websites that can be generally trustworthy.

Blood Cancer United

I'd also encourage patients to sign up for newsletters or mailing lists from some of these reputable sources like Blood Cancer United, CLL Society. Patient Power is one that I personally really like. That way the info comes to you, instead of you having to seek it out.

So, in the end, educating yourself is about having a greater sense of control in what may otherwise feel like a powerless situation.

Elissa: Yeah, yeah, and one thing I really liked that Annette did, is she has access to medical journals, and she's used to reading those. So, she was sending them to her doctor and said, "Hey, what do you think about this?" And even though we don't necessarily say that patients need to do that, that's why we have resources like this that have treatment options available so they can go back to their doctor and say, "Hey, what do you think about this? Do you think it would be good for me?" And we want patients to be able to understand their disease enough to be able to go back and ask those questions.

And I do want to point out that we have a great resource regarding shared decision-making for CLL patients, in particular. It's an interactive program for chronic leukemia, so we have CLL and CML (chronic myeloid leukemia) on there. And it takes you through scenarios about how to talk to your doctor and questions to ask and ways to interact so that you are getting all the information that you need – you're understanding the pros and the cons and the benefits of all of these medications and

Blood Cancer United

treatments or watch and wait and, really learning how to communicate with your doctor. So, we'll have a link in the show notes for that really cool program to go and check out.

But thank you so much, Elise, for joining us and delving a little deeper into things that Annette had talked about. And so, we hope this was a really comprehensive view of CLL for patients and caregivers that are listening today. And so, again, we really appreciate you joining us.

Elise: Oh, absolutely. Happy to be here, and if patients are ever looking for somebody to chat with and do a little bit of one on one, hey, this is my situation, we're always here to lend an ear.

Elissa: Yes, definitely. And if patients are looking for clinical trials at any point after diagnosis-

Elise: Absolutely.

Elissa: -you are a great place to go to, the Clinical Trial Support Center. And we'll also have a link for that in the show notes so that they can get connected and see what is available for them. And so, again, thank you so much.

Elise: Absolutely. Thank you.

Blood Cancer United

Elissa: And thank you to everyone listening today. *The Bloodline with Blood Cancer United* is one part of our mission 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 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.

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 Blood Cancer United staff, please email, TheBloodline@bloodcancerunited.org. We hope this podcast helped you today. Stay tuned for more information on the resources that Blood Cancer United has for you or your loved ones who have been affected by cancer.

Blood Cancer United

Have you or a loved one been affected by a blood cancer? Blood Cancer United 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 BloodCancerUnited.org/PatientSupport. You can find more information on chronic lymphocytic leukemia at BloodCancerUnited.org/Leukemia. These links and more 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.