Webinar Transcript
Shared Decision-Making in CLL:
Partnering With Your Doctor to Choose the Right Path
May 27, 2026

In science and medicine, information is constantly changing and may become out-of-date as new data emerge. All articles and interviews are informational only, should never be considered medical advice, and should never be acted on without review with your health care team.

This text is based on a computer-generated transcript and has been compiled and edited. However, it will not accurately capture everything that was said on the webinar. The time stamp is approximately 10-minutes off due to editing. The complete recording of this webinar is available on-demand.

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Hello and welcome to today's webinar. I am Liza Avruch, Program Director with the CLL Society.

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We are dedicated to bringing credible and up-to-date information to the CLL and SLL community because we believe smart patients get smart care.

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As a reminder, you can rewatch all of our educational programs by going to the section of our website called Education on Demand.

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Prior to beginning, we'd like to mention a few pre-event items.

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All attendees in this webinar are muted and the only people on camera are the speakers.

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We ask you to please direct all questions to the Q&A section displayed on your screen.

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Questions will be sent directly to our moderator, speakers, and staff and are not visible to the audience.

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After today's event, you will receive a very brief survey that will help us plan for future events. We greatly appreciate your feedback.

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This session will be recorded and made available to everyone on our website.

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Closed captions are available, if you want to turn them on or off…

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go to captions and select show captions or hide captions.

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This program was made possible through donor support and grant support from our industry partners.

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At this time, I'd like to welcome our moderator. Thank you.

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Thank you, Liza. Welcome, everybody. My name is Stephen Feldman. I'm a CLL patient currently in my ninth year of remission, a longtime CLL patient advocate, a member of the CLL Society's Patient Advisory Board, a senior group advisor, and for the past 10 years…

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co-facilitator of the City of Hope CLL Society Support Group.

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I'd like to welcome you to today's webinar, Shared Decision Making in CLL: Partnering with Your Doctor to Choose the Right Path.

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We're joined today by Dr. John Burke and fellow patient advocate Christina Fisher. They'll be discussing the importance of shared decision-making, an approach in which patients, clinicians…

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and care partners work together to make treatment decisions that reflect both the best available medical evidence and what matters most to the individual patient.

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We'll also be taking audience questions at the end of the program, so please feel free to submit your questions using the Q&A box.

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Before we begin, I'd like to share a few brief disclaimers.

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The information provided during today's webinar is for educational purposes only and should not be considered medical advice. For personal medical questions or treatment decisions, please consult your health care team

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Please also note that while the CLL Society may have its…

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perspectives and policies, our speakers may offer differing viewpoints, particularly regarding the management of CLL and its complications. And now, it's my pleasure to welcome Dr. John Burke.

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Hello, everyone. My name is John Burke from Rocky Mountain Cancer Centers and I'm pleased to talk to you today. The title of my talk is Shared Decision Making in Partnering with Your Doctor to Choose the Right Path.

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These are the take-home messages that I will come back to at the end of the talk, but I wanted to give you a preview of the two most important points that I would say I'm going to try to make today. The first is that patients with CLL essentially always…

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Have choices about which treatment they wish to receive…

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and secondly, that shared decision-making means that providers and patients work together to create a treatment plan. And, you know, both providers and patients have a job in that relationship. The provider's job is to…

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educate the patient so that the patient can make the best informed decision for themselves. And in the era of the Internet and now of artificial intelligence...

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patients really have the power to educate themselves effectively, and such education can supplement the education that's provided by the physician. So those are the two...

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take-home points, and we'll, as I said, come back to that at the end and review that. And just so you know that...

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you know, I didn't just come up with that for this CLL talk. Shown on this slide here is a quote that I have had on my professional website for my organization, Rocky Mountain Cancer Centers, for as long as I can remember...

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well over a decade, and this describes my own personal philosophy of my job as a physician and the philosophy of medical care, and I'll read it to you, just to drive the point home. I believe that the role of physicians is to educate patients and to help them…

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make the best decisions possible regarding their own care. The idea that physicians know best and should dictate treatment to patients is archaic. Instead, physicians serve as teachers by educating patients about their diseases…

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and their treatment options and helping patients select the best treatment for their situation. So that continues to be my philosophy of my job as a physician. It's how I try to practice every day, and I think that…

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drives home the importance of shared decision-making in the interactions between physicians and patients.

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And the next few slides here I have are going to show you that at every step of the way along a CLL journey, patients have choices, and the first choice starts with the watch and wait…

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process that most patients with CLL go through once they're diagnosed. Most patients with CLL do not require treatment immediately. The disease is found and patients go through this process of watch and wait that often lasts for many years before treatment is initiated.

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And what I've summarized here in this table is international guidelines that describe when patients should start therapy for CLL after this period of watch and wait.

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And you can see the indications listed on the left-hand column, and then I have a few comments about those indications on the right side of the table. And the first two at the top that I've listed are relatively black and white. The hemoglobin is the blood value on the CBC, indicating how many red cells you have in your blood…

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and if that number is less than 10, that's an indication to start treatment. Similarly, if the platelets are less than 100, that's an indication to start treatment. Even there, there's some variability and some judgment call used, but those are fairly black and white. And as you go down, it gets a little more complex. Massive or symptomatic…

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lymphadenopathy, meaning enlargement of lymph nodes. You can see on the right, well, is it causing any physical discomfort, or is it blocking any vital organs? There can be some judgment call in assessing that. The massive or symptomatic splenomegaly, is it causing pain or early satiety? That means getting full when you're eating a meal.

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Progressive lymphocytosis is if the white cells are going up really fast, and then the second to last one, they are constitutional symptoms. Fatigue is really common in patients with CLL, and it's tricky to sort out, well, is the fatigue from the CLL, is it from something else?

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And so, is the CLL making a person feel bad? There's a lot of subjectivity there. And so, the point here is that these are the indications to start, but there's…

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probably more grey zone than black and white here in terms of deciding when to start, and there's a lot of back and forth in my experience, between physicians and patients on deciding when to start in the first place.

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Here, we have listed the options for first line or initial therapy for CLL after that decision has been made to start treatment. The point here is the same. You've got several options for how to be treated.

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And the top row there, you have the combination of venetoclax plus the CD20 antibody. This is a one-year so-called fixed-duration therapy. You get the one-year treatment and then you stop. This has some advantages and some disadvantages, shown in the column on the right.

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A second option is to combine, is to take a covalent BTK inhibitor, such as ibrutinib, acalabrutinib, zanibrutinib. This is not one-year fixed-duration therapy. Instead, this is indefinite therapy that's continued until the patient becomes intolerant of the treatment or the disease progresses.

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And so, you could be on this treatment for 10 or more years, so a very different scenario than that first option. And the third option is a newer one, where you can combine venetoclax and the covalent BTK inhibitor and that can be done in a couple ways. That can be taken for…

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about a one-year fixed duration therapy or it could be done for a longer period of time, perhaps with testing called minimal residual disease, or MRD, to drive the duration of therapy. So, a whole bunch of different strategies can be used…

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for initial therapy for CLL, and there has to be this process of shared decision-making for an individual patient to decide what is best for themselves.

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The decision-making process does not get easier when you get on to second-line therapy, because a lot of what you get as second-line treatment depends on which of those options you got in the first line. There's a lot of variability. So an example here, if a patient was intolerant of a covalent BTK inhibitor, after a while...

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they could try a different covalent BTK inhibitor or they could go to a non-covalent BTK inhibitor like pirtobrutinib or they could totally switch mechanisms and go to venetoclax plus a CD20 antibody. So, several options to understand and choose between.

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Second option, if a patient progressed while on a covalent BTK inhibitor, their CLL got worse and is now resistant to that drug. Well, they can go on to a non-covalent BTK inhibitor like pirto, or they could switch mechanisms and go to venetoclax plus the CD20 antibody. I won't go through the others, but just the point is the same, that there's going to be several options depending on…

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what you got first line and what treatments you've received before. And it's really no different when you get to the third line. You know, patients can get a noncovalent BTK

inhibitor pirtobrutinib if they haven't gotten that before. There's CAR T-cell therapy available, there's allogeneic transplant available...

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we can even use PI3 kinase inhibitors or chemotherapy and some other options as well. So, there's always options that can be considered, and that doesn't even consider the fact that at every step of the way, a patient can consider going on a clinical trial that's testing new therapies. So, I wanted to…

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make sure that patients understand that this is often going to be an option for them, and it's not a requirement, but these trials are testing new treatments for CLL, and just to make some points about these, you should know that all of these trials are reviewed by independent panels to make sure they're being conducted in an ethical…

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fashion. In my personal opinion, participation in clinical trials should be considered an option, but it's not a requirement. I don't try to put pressure on my patients to enroll in these trials, but this is how we advance the field in CLL…

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and how we advanced the field of human disease in general. Without these trials, we would never demonstrate improvements in outcomes with new therapies. So, it is how we advance medicine and treatment of human disease. We all have benefited from those who have gone before us and participated in these trials.

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And I will tell you, and this is on my website as well, when I get cancer, or I put insert disease here, I will likely be signing up for a clinical trial, and I say this really because I am confident that clinical trials offer good treatments to patients, and I personally want to make that contribution to science and humanity…

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in the future so that those who come after me will benefit from my participation in these trials.

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So, what kind of questions should patients ask their doctors when they're thinking about all these things? And I list some really important factors on the left there that can affect one's decision as to what kind of treatment you might want to receive.

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One is, what are the side effects of the drugs I'm going to receive? You know, that might be important for you, that you have a preference. So, if something happens to me, I would rather it be side effect A but not side effect B. That could be important to you, so that's an important thing to understand.

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What about the impact of your underlying medical problems? Those might impact the treatment choice, and the classic example in CLL is if somebody has atrial fibrillation, a cardiac arrhythmia or if somebody has a bleeding tendency or has to be on a blood thinner.

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That might steer you away from drugs that can make those worse. That's the BTK inhibitor category. You know, what about current medications? The drugs that we use in CLL do frequently have interactions with other medications that patients are already taking…

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and if those are critically important and can't be modified, that might steer you towards one drug and not another, or it might be that you want to adjust that medicine you're already taking so that you can get a treatment that you prefer for your CLL. So, these are important considerations.

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Something as simple as a travel requirement might impact the treatment that a patient wants to get. If you're a frequent traveler and you want to be out of town a lot for, maybe for some extended periods, that might steer you away from a treatment that requires frequent visits to…

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the provider for lab draws.

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And then there's a big difference between fixed duration therapy and continuous therapy after that first year, you know? You're off of all treatment after one year if you get a fixed-duration therapy. There can be differences in cost, and then sometimes there's biological differences, where we think one treatment might be a little better than another depending on the biology and the gene mutations that are…

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in the CLL, and so that…

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can impact a decision about treatment as well. So, these are all factors that can impact a patient's decision about what treatment they want to receive and that can be discussed with the physician.

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That brings me to the benefits of getting a second opinion here in this table. I've listed advantages and disadvantages of doing that. There's really not a lot of disadvantages, but I do list some. You know, the advantages of getting a second opinion are that you can get additional education. It's another source of education and information about standard treatment options. You might also get additional information about…

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a clinical trial option that was not present at the first institution at which you were seen. And even if you don't learn anything new, there can be value in having the information you already have learned be reinforced, and maybe you'll come away from that second opinion saying, well, I didn't learn much…

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new but I did learn that my first doctor told me everything correctly, and that the second doctor totally agrees with the suggested plan, and that can be very reassuring for patients, and that in and of itself provides value.

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And then the fourth thing I list there is that the opinion you will get will likely be from someone who's a specialist and therefore highly knowledgeable about CLL. You've probably chosen that individual to provide a second opinion because they are an expert in your disease. On the list of downsides, it does take some time and effort. Sometimes it may require you to travel, which can cost money.

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We'll hear later that the CLL Society has taken some steps to help overcome that barrier. After all that effort, you may not learn a whole lot that's new. It might feel that it wasn't all that worth it. I would say that's unusual, but it's possible.

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And that the clinical trials that you may be offered if you've traveled to a different site, you know, may require that you receive your treatment in that location, and that can be unrealistic for people to move or travel frequently back to a particular location for a clinical trial, especially if it involves…

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regular plane travel.

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Here, I point out that, you know, you can, you as patients can educate yourself, and I've listed websites that I think are valuable here. The CLL Society provides excellent education, and I've listed their website here, and they have a lot of written information for those who don't want to read on the Internet about CLL. So, lots of resources provided by the CLL Society that patients can use to educate themselves.

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And I list a couple of others here, Blood Cancer United, formerly known as Leukemia and Lymphoma Society, has educational material. The American Cancer Society and American Society of Clinical Oncology have partnered to create educational material for patients and they have a section on CLL that's broken into…

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several sections, and there are many others. This is just far from an exhaustive list of educational options that you can use to learn more about your disease.

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And that, of course, brings us to a new way of learning about your disease, which is artificial intelligence. This is a list of some commonly used websites and AI programs, and I've played around with all of these, some more than…

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others and to the right here in the comments section, I list some of the features of each. I'll comment I have probably the most personal experience with the Google Gemini and also with the Open Evidence one that's listed there, which is provided free…

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for physicians. So, these are also ways that one can learn about CLL, and here in this table, I want to hit some of the advantages and disadvantages of these. You know, using AI can quickly provide, in my opinion, quite reliable information about diseases…

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and it sort of avoids the problem of having to know what's the best website or a reliable website and which aren't. I know a lot of patients come in to see me and they say, well, I just stayed off the Internet because I don't know what I can trust out there. And, you know, I think for the most part, AI will give you good answers if you go in and type into one of these things, what is chronic lymphocytic leukemia, it's going to give you a pretty good answer. And that can be a way to get you started.

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It can be used to prepare patients for efficient and effective meetings with your doctor. So, I did this myself when I went into one and said, I have a new diagnosis of CLL.

What questions should I ask my doctor about CLL at our first visit? And it gave me a very nice list of questions that stimulate some thought and that you could bring in and use to make sure you get all the information you need about CLL. And it provides a direct conversational summary…

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of whatever you ask it. Disadvantages, it can give false information, and it is recommended that you doublecheck what it gives you, and I'm not sure that all AI sites are equally good, and I put a couple of quotes from Gemini.

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I just point out that they themselves have very clear disclaimers on their websites that say, hey, we can make mistakes, and this is informational, but for medical advice or diagnosis, consult a professional. So, there's disclaimer on these that say user beware. It certainly cannot help in a medical emergency. I'll point out, a lot of people don't think about this, it's not governed by medical privacy laws…

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so if you scan in your report and it has your name and birthdate on the top of the page, you're providing that information to these AI programs. And so...

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it's probably a good idea to white out that information so that it doesn't know who you are when you're uploading your own personal documents. And then, as I was preparing for this talk, I learned about something that I didn't know before, which is called sycophancy, which is the tendency of AI to tell you what it thinks you want to hear.

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That is, if you get in a long, extended conversation with AI, it can tell from your...

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you know, input that you don't want to receive treatment for CLL or something, that you have your biases and opinions, that may impact the answers that it gives you back, and so it's important to recognize that this is a potential flaw…

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in the use of AI. So, my suggestion for use of AI, I think it's good to get information about your disease, it's good to prepare for your appointments. I would use it as a supplement to, but not as a replacement for information from your provider. Keep in mind the disclaimer that it can make mistakes and give you wrong information. Therefore, doublecheck what it's telling you.

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Don't give it your personal information. Beware of the fact that your own biases can influence its responses to you once you get beyond the simple, what is CLL-type questions.

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And it's, there's no shame in using this, I use it all the time, so be open, you know, it makes sense to be open and honest with your provider about using it. If you have a question about something you read on it, just let them know, hey, I got this off of that AI website, what do you think of this information?

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So, back to my summary slide here, that patients with CLL essentially always have choices about what treatments they wish to receive. This shared decision-making process means that providers and patients work together to educate about the disease and create a treatment plan. The provider's job is to be the main source of education for the patients...

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recognizing that patients have access to many other sources of information that give them the power to educate themselves effectively and thereby make the best decisions they can for their own healthcare. And such education can come from…

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places like the CLL Society, it can come from AI, and it can come from second opinions, and most importantly, your physician. And that's all I have. And so, thank you for your attention, and I would now like to introduce…

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Christina Fisher.

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Thank you, Dr. Burke.

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I'm Christina Fisher, a CLL patient presently in remission, a longtime CLL patient advocate, as well as co-facilitator of the Portland CLL Society Support Group.

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I'm an overly active mom in a blended family of three grown kids and living in Boring, Oregon with my partner of over 20 years. He's also my caregiver along with my oldest daughter.

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I've been on this journey managing my CLL, SLL for 13 years, diagnosed at 51 while working for a local hospital system and quickly went from patient to advocate and activist.

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I enjoy spreading messages of hope about CLL, SLL and co-facilitating for the CLL Society's Portland, Oregon group in between mountain biking, skiing, and many other physical activities.

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At the time of my diagnosis, I had been misdiagnosed for a year, and then told I had two to 10 years of life so get my affairs in order.

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At the time, watch and wait seemed like an appropriate moniker to label my feelings.

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Everything about my active surveillance at the time confused and somewhat alarmed me. I decided I must advocate for myself.

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My daughter was a medical intern and she immediately sent me six months of the blood cancer journal magazine…

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that I read cover to cover.

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Also, heeding the advice from the CLL Society's website, I had my medical file sent to the Leukemia Lymphoma Department at our local university teaching hospital, OHSU.

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Then quickly, a renowned CLL, SLL specialist, Dr. Alexey Danilov, contacted me to discuss my care in 2014.

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I moved from a hematologist-oncologist at a different hospital system to my specialist.

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After three years of active surveillance, my health declined suddenly at an alarming rate

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Dr. Danilov excitedly discussed a recent Phase II clinical trial with me, stating that my younger age…

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and excellent heart health made me a great candidate to join the sooner the better.

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I was introduced to his team. They were highly informed and intelligent...

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cohesive, energetic, and fun.

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This combination convinced me that seeking a specialist is one of the most important decisions a patient can make.

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Being up-to-date on the latest treatments, he was convinced that we were looking at a new horizon of less invasive and hopeful treatments.

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I took some time to let it resonate and talk to my family, making the decision to join in less than 24 hours.

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I was already well-read and prepared. I also belonged to a forum that was comprised of patients only, blatantly sharing their treatment journeys from all over the world.

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Within four days, I started 400 milligrams of oral medication TGR-1202.

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Now, umbralisib, a PI3K inhibitor. It was not eventually approved by the FDA for CLL.

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It was a large dose for my size and I battled many side effects, including hospitalization for electrolyte failure and some minor cardiac nerve damage...

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five hospitalizations for dehydration.

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While on this oral medication, I started newly approved Gazyva, or obinutuzumab, by IV as part of combination therapy…

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with Benadryl for reactions and dexamethasone, a steroid for battling fatigue after infusions.

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I had an immediate reaction and became violently sick. We discontinued and restarted with a lowered dose. I stabilized with no further issues.

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After stopping the 24-month treatment at the conclusion of the trial, I relapsed six weeks later. I was terrified that it was Richter's transformation but it was not. A very concerned Dr. Danilov highly recommended Venclexta or venetoclax, which had been recently approved and was used in combination with rituximab...

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promising a deep remission following a triple combination with the recent Gazyva.

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Venetoclax had just been approved. OHSU obtained it for me, being the first woman in Oregon to receive it.
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I was hospitalized for a week while I started my doses to watch for tumor lysis while curiously watched.

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There were tiny lab signs, but mostly I took walks with my IV hydration, did art class in the ward, and ate too many meals.

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The whole experience was much easier as the technology improved.

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After taking 400 milligrams Venclexta for many months, I wasn't tolerating the full dose well, so we reduced the dosage down to 300...

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200, then 100. Starting rituxan IVs, and eventually rituxan hycela injections, which were also new.

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This seemed scariest to me. A stomach injection that I panicked over, and I was proven silly with a shot lasting six minutes versus a five-hour infusion visit.

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By this time, I was driving myself to my appointments with my laptop and my lunchbox.

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A four and a half year journey that started a little rough transitioning to an easy routine. After 25 months, I was tested by flow cytometry for measurable disease and there was none.

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It's taken me a few years to feel like myself again, enjoying 60-plus months of UMRD, detectable…

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measurable residual disease.

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I have not had a bone marrow test yet, and I am on a tiny dose of heart medication which corrected a post-treatment issue, but I just had a great checkup with my cardiologist and my oncologist.

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Finding the right physician who specializes in CLL, SLL makes all the difference. The confidence is reassuring, along with the proper determination for treatments and combination therapies for you. When I chose my specialist...

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someone from an online forum recommended I start a large notebook binder because of the marathon mentality, and they were right.

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I gathered all new information, printed articles, and took notes from forums so that I could write my questions down and have them ready for my specialist at check-ups.

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I started sending them to my clinical trial head nurse prior to visits so they could be prepared with my answers and concerns. Getting a second opinion is crucial for the best treatment journey and results.

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Make sure if you are seeing a hematologist or general oncologist that you can obtain a second opinion from a CLL specialist.

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If there is not one nearby, then use the Expert Access program that the CLL Society offers so you can receive a consulting opinion virtually.

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This disease is heterogeneous. It displays and behaves differently in every patient, and a specialist can determine and implement the best treatment plan for you. I have found that some of the best advice comes from the hard-earned wisdom and emotional balance that can only be offered by fellow CLL patients and care partners…

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who have already experienced the challenges you are facing, or the therapy you may be considering. CLL Society support groups are an important resource for education and emotional support.

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For those in watch and wait, there is a great benefit to attending support groups with people who have a range of treatment experience for their CLL or SLL. In addition to joining a local support group, there are also support groups for veterans with CLL...

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satch and wait, CLL patients without a care partner...

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young people with CLL and physicians with CLL. All support groups are currently meeting virtually through Zoom. In addition to support groups, the CLL Society offers opportunities for one-on-one support.

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The Peer Support Program is an opportunity to connect with another person impacted by CLL who can talk with you one-on-one and help answer questions around many topics based on their own experience.

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The Ambassador Program connects you with a fellow CLL patient for treatment-specific questions; whether you are considering a targeted therapy or CAR-T therapy.

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The Emotional and Spiritual Advocate Program provides one-on-one support with a board-certified chaplain for those of all faith or no faith background.

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You can find information for all three programs on the CLL Society website and sign up to schedule a phone conversation.

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I used the time during watch and wait to learn about CLL and my treatment options.

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The online CLL SLL Patient Education Toolkit is a great way to learn a broad spectrum of information, including the basic biology of the disease, treatment options, and other helpful topics.

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Each topic is presented in patient-friendly terms and can help inform you for deeper discussions with your healthcare provider. The CLL Society Medicine Cabinet includes nine of the most commonly prescribed CLL medications in patient-friendly language.

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You can find this resource included in the Patient Education Toolkit and promoted on the CLL Society's home page.

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Each treatment page includes helpful information on dosing, common side effects, and how to manage side effects. Special considerations, links to financial resources from industry and more. Another great resource that the CLL Society provides is the Normal Lab Values Chart..

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and the tracker you can download and use the tracker to record your routine blood test results.

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In CLL, it's often not one lab report that tells the story but whether levels are trending up or down over time that can inform your questions and decision making.

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It is more than likely that you will be seen by different providers and have blood work performed at different labs.

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The lab tracker then becomes an important resource where you can have the history of your results entered and displayed in a single document.

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You can take this tracker with you to the medical appointments if meeting with a new doctor or to better inform discussions with healthcare providers. It is valuable to have predictive genetic testing completed at the time of diagnosis.

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It is critical to have genetic testing completed prior to the first and every subsequent treatment.

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The CLL Society's Test Before Treat Campaign highlights the three genetic tests that are essential prior to treatment. These include FISH...

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IGVH and TP53.

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To support patients and care partners, there is a downloadable one-page sheet available on our website.

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It is recommended that you bring the Test Before Treat document with you to your medical appointments to help inform this discussion.

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Putting together your team early on in your journey is important to have a support system in plac.e

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The world expert is a doctor who lives and breathes CLL, who will direct your overall strategy and who has access to the latest therapies and clinical trials.

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You may not see this doctor often, but they are accessible for important conversations.

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The local expert…

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is your local oncology or hematology doctor. CLL patients are at a higher risk for second cancers, especially skin cancer…

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so your other healthcare team should be in place too, including your dermatologist and primary care doctors.

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A financial navigator can include a financial counselor or social worker.

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This could be a close family member or friend who is willing to help.

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Personal support can come in many forms…

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and there are numerous benefits to joining a CLL-specific support group that I will share.

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Download CLL Society's helpful list and put your team together. The best way to stay informed about breaking research, news, education, and events is through signing up for the CLL Society's This Week email newsletter that is sent…

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every Tuesday.

00:47:31.000 --> 00:47:36.000
You can find the CLL Society on Facebook, X and LinkedIn.

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Use this time to get educated about CLL and SLL and become a self-advocate in your healthcare.

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The CLL Society provides many tools and medically curated information to support you.

00:47:50.000 --> 00:47:55.000
Put together a team and include a CLL expert physician.

00:47:55.000 --> 00:48:03.000
Stay informed with what's new through the weekly email and continue to join us for these important webinars.

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Thank you so much for your time. We will now open the program up to audience questions.

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Thank you so much, Dr. Burke and Christina. We appreciate your clear and helpful presentations. We're now going to move into the Q&A portion of the program.

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We'll do our best to get to as many audience questions as possible. Apologies in advance if time doesn't allow us to answer every submitted question.

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Please feel free to reach out to us afterward with your question at the trusted care exchange email address, which we'll share on the closing slide. Someone asked me a question, they congratulated me on my remission and asked about what my treatment options were.

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Briefly, that was a long time ago now. I was diagnosed in 2014, with pretty good markers, “deletion Q13” (deletion 13q or del(13q)) and trisomy 12. I was in watch and wait for…

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a surprisingly brief period of time, started treatment in 2017 on a combination of ibrutinib and Gazyva obinutuzumab. Venetoclax wasn't even approved at the time for frontline treatment, that's how long ago it was. So, with that, I'm going to…

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yeah, first question for Dr. Burke.

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Patients today often arrive having read websites, watched videos, or even used AI tools before seeing their doctor. In your view...

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what does a well-prepared patient look like? And just as importantly, what approaches do you take in your practice to help patients feel comfortable becoming true partners in the decision-making process rather than simply passive recipients of information?

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Yeah, thanks for the question Stephen. I think people come in at different stages of the game, at least in my practice, where I'm in a community practice, not an academic center. I see patients…

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who have CLL but don't know it yet. So, I'll see patients who come to me because their primary doctor found…

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a high lymphocyte count or high white blood cell count on a routine CBC, so they come to me with no more information other than that, and they don't know that they have CLL. So, that's an example where…

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the patient, it's hard to come in sort of really well-prepared and knowing a lot about CLL because you don't even know you have it yet, you know? So, for me, the preparation and the education is an ongoing process. It's not something that all has to be accomplished in one visit...

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it's a long-term process, as Christina outlined beautifully. You know, you have this not everyone, but you often have this sort of watch and wait period, which it usually lasts many years. So there's, you know, often it's plenty of time for patients to sort of get educated about their CLL and…

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so, I would encourage people not to stress out if they, you know, don't know everything there is to know about it the very first time they go in, or if some of the conversation feels like it's a little bit over their head. Take your time and use all the resources that have just been beautifully outlined for you by Christina…

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that CLL Society provides to get educated, and so really, that's what the prepared patient does, is take their time and learn about the disease over time.

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Yes, and there's…

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remind me the second part of your question.

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Okay.

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Oh, it said, well, actually I already deleted that question because I'm trying to consolidate my list on my screen. So, I'll just add that, you know, in my group, we have lots of members…

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who, had been participating in the group for years, they still haven't even begun treatment yet. So, it's very rare, in my experience, that anyone's in a rush to make a decision. And usually you've got, it is an indolent disease, it's a lazy disease, so…

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most people have lots of time to front-load their knowledge.

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Oh,…

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next question is for Christina, and Christina, I'm going to bundle a bunch of questions, so you'll have to do a better job than Dr. Burke to remember all of them. So, what are your suggestions for finding a CLL doctor? And was there a point in your CLL journey when you realized that being an informed patient…

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didn't mean becoming an expert in everything. And for people who are newly diagnosed or still finding their footing, what do you wish someone had told you earlier about participating in your own care?

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Okay, let's see if I can get all these.

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Thank you for your question. So, finding a CLL specialist, well, a really great resource is on the CLL, excuse me, CLL Society's website under the Newly Diagnosed heading…

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and you can search physicians by state and find all of the physicians that are labeled as a CLL specialist.

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And that is actually, how I found mine to begin with. And I had been seeing a hematologist…

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who was not a specialist.

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And that kind of comes to the question when you're asking about not becoming an expert.

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It was a lot of information to take in up front as a patient, and it was difficult to sift through all of it. There were several websites that were out there that…

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offered all patient information. Some of it useful, some of it scary…

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and after I'd been diagnosed for so long, I began to distrust my physician and was really looking for expert guidance.

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So, when I found my specialist, which that is my advice is to find a specialist and go straight to them. If you can't go straight to them, then send your records. Use the Expert Access Program of the CLL Society...

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always get second opinions…

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and…

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finding the right specialist who provided current information, future treatment information, specialists typically have access to these clinical trials. These trials are imperative.

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So happy that I did one. I feel like maybe I made a contribution, not just for myself, but for others.

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You know, sending a message of hope with it. So, finding that specialist and getting all of that…

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higher level of information…

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I think it caused me to relax.

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I was able to just let someone else take the wheel a little bit more.

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Christina, do you think you, for the audience, can you distinguish between a CLL specialist or a specialist and an expert…

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and I'll answer it if you don't think you can.

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Boy, I mean, I know I would consider an expert to be someone that has had their hands in clinical trials.

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What have you got?

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Because I think people often think that a specialist is just somebody who has a subspecialty in hematology and oncology. That doesn't necessarily make them a CLL expert. That's why I just want to make a fine point on that terminology.

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So...

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I also wanted to add that, in my experience, when I was diagnosed, I was living in New York at the time that I got diagnosed and met with an expert just a few days before moving from New York to California, and the doctor that I was seeing when I moved out to California, I would not…

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qualify as a CLL expert, and when we started the City of Hope support group, which was, which is now 10 years ago, I was introduced to the doctor who ultimately has been taking care of me. He's a CLL expert, and that changed the course of everything.

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Had I not discovered that expert, I might very likely have gotten chemo immunotherapy, which my expert had given up on years before. So, finding that expert is…

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key. Okay, I'm going to jump to a question for Dr. Burke. When does CAR T-cell treatment become an option?

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Yeah, thanks for the question. I think right now there's one CAR T cell product that's approved to treat CLL. It's calledLLiso-Cel it is approved for patients with CLL after they've received at least two prior therapies. And basically, that means they've received at least…

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a BTK or Bruton tyrosine kinase inhibitor like ibrutinib, acalabrutinib, or zanubrutinib, and the BCL2 inhibitor venetoclax. So, you have to have received at least both of those in the past, and then have your CLL get worse in order to qualify for…

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CAR T-cell therapy. And that's really because of where it's been studied and it does have…

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not insignificant toxicities in CLL, so that's the current placement for it in the guidelines where it would get approved by insurance and where most Docs would recommend it for you. Reality is that most people would also go on to receive the non-covalent BTK inhibitor pirtobrutinib before…

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getting a CAR T-cell therapy, it's not required, but most people would get that first. So, in reality, I would say it's usually a fourth line of treatment or beyond.

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There are some clinical trials investigating the delivery of CAR T-cell therapy sooner than that, waiting that long…

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but that's sort of being used for, usually for highly, patients at high risk of their cancer getting worse, sort of high-risk CLL and earlier lines of therapy. So standard approach to use of CAR-T right now is really…

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third line and beyond, and usually fourth line therapy.

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Thank you for that. I'm going to try and combine two questions here...

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related. Someone writes, if you have bad numbers…

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but still no symptoms is it the time to start treatment? The follow-up question is, or related question is, my labs are good, but I'm always tired...

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why?

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Yeah.

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So, the first question by bad numbers probably means a high white blood cell count and high lymphocyte count. And typically, our answer to that is just the absolute number of lymphocytes does not necessarily drive the decision to treat.

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That's probably the most common question I get in the clinic is, at what white blood cell count do I start my treatment? And there is no answer to that question. That is, we don't usually use just the white blood cell count or the lymphocyte count to decide on when to treat. Instead, the kind of international…

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agreed upon guidelines are that you should have anemia, meaning a drop in your red blood cells, low platelets, or some other problems related to CLL, like the symptoms that you mentioned, or autoimmune complications, and so there's other things besides the white count. Now, the sort of exception to that rule…

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is not the white count itself or the lymphocyte count itself, but the rate of increase. That is, it is acceptable to initiate treatment based on a rapid rise in the lymphocyte count over time, and the usual number, we say is if your lymphocyte count is doubling…

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every six months or less, that means kind of the writing is on the wall, you're not going to be somebody whose CLL stays stable for years and years and years, so you're probably going to need treatment sooner rather than later, and that's a scenario that we will sometimes use that indication to treat somebody's CLL.

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Once again, I forgot the second question. Oh, CLL and fatigue, right?

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Yes.

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Yeah, so fatigue and CLL is a complex subject. I alluded to it a little bit in my talk, and what I see in my practice, and you guys don't have the benefit of sitting in my shoes, but I take care of CLL, but also other lymphomas and some other diseases, and I would say…

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a lot of people, a lot of patients in my practice come in to me and have fatigue. And that number may be as high as 90% of the people who walk into my clinic report fatigue. And when someone has fatigue and CLL at the same time, the question I have to try to sort out with them is....

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is the fatigue due to the CLL? And if so, the corollary is, does this person need treatment for their CLL because it's causing them to have fatigue? It's a complicated issue. I always sort of try to look for other causes of fatigue, try to understand the severity of the fatigue. How much is it impacting somebody's life…

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and quality of life. Is this just kind of afternoon fatigue that requires them to take a nap and then they feel better? That's no big deal. But if it's really impacting somebody's life, and they feel like their quality of life is impaired, that's a more serious level of fatigue.

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Definitely CLL can cause fatigue. I also look at the stage of the CLL. If it's very early, let's say somebody just has a slight increase in their lymphocyte count and no lymph node enlargement, and no spleen enlargement, and no anemia, that person's fatigue is probably…

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unrelated to their CLL, when they have very early stage disease. Whereas when they get more advanced and they have a really high white count, that fatigue is more likely to be due to the CLL. So, it's tough, it's a lot of back and forth. If somebody has CLL and their only symptom is fatigue…

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I usually don't treat them or I try not to treat them, but there have been exceptions where people are really sure their fatigue is due to CLL. In that case, I'll go ahead and

treat them, but I would say that's the relative minority of reasons I initiate treatment for folks.

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Does the fatigue respond to treatment?

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You know, and the answer is it's complicated there too. The drugs we use can cause fatigue. And so just because you're on therapy doesn't necessarily mean your fatigue is going away. I will tell you that those who I have treated…

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purely for fatigue, tended to have pretty advanced CLL anyway, and I will tell you, they thanked me for it and said their fatigue got better.

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That's great.

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Someone writes, I'm newly diagnosed within the past two months. I've heard of FISH testing and karyotyping for CLL.

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Do you recommend these and how do these inform us?

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Thank you. Yeah, so there's, Christina shared a slide about some of the important prognostic markers that are recommended for patients with CLL, and the most important prognostic markers that we focus on…

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these days are the results of the FISH testing.

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The results of gene sequencing of a gene called TP53 and the results of the IGHV mutational status.

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Karyotyping is another way of looking at large chromosomes, and that also has some prognostic significance in CLL. Generally, I do it on a bone marrow biopsy, although it can be done on peripheral blood, but that doesn't mean I get a bone marrow biopsy on everybody.

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So, if I'll do karyotyping myself, largely when I'm starting someone on treatment, and if we decide to do a bone marrow biopsy, I'll do karyotyping then.

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The other three tests are routinely done on the peripheral blood and the FISH is looking for…

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certain gene abnormalities that we know to be common in CLL. Most CLL FISH panels will test for six or seven different gene abnormalities that have prognostic implications for CLL.

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And of those, the most important one is deletion of the short arm.

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Chromosomes have a long arm and a short arm. Deletion of the short arm of chromosome number 17, that's abbreviated 17P. So, you'll see that those who have a deletion of 17P have a less favorable prognosis. That abnormality is closely related to the gene…

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called TP53, which is located on chromosome number 17P, and you can sequence the TP53 gene, meaning if you go back to your ninth grade biology, where you learn what DNA consists of, these base pairs, A, T, G, C...

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you're actually doing that sequencing of the gene of TP53, and if there is a mutation in TP53 that has a less favorable prognosis than absence of a mutation of TP53. So, those are the prognostic markers that we try to look at in our CLL patients when…

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we were trying to decide what kind of treatment to give them.

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Yeah.

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You mentioned bone marrow biopsies. There's often a lot of confusion about, do I need to get a bone marrow biopsy, do I need it for diagnosis? When does that come into play?

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So, it's not needed for diagnosis. And by the way, I got the same question yesterday from a physician. So, physicians don't even know the answer to this question. So, a bone marrow biopsy is generally not necessary to diagnose CLL. When you come in with CLL, you usually have the malignant cells…

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which are lymphocytes, they're floating around in your blood, and you can do really all the tests you need on the blood lymphocytes to diagnose CLL. So, I usually do not do bone marrow biopsies on my CLL patients, although sometimes if they're diagnosed elsewhere, they'll come in having had them done.

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Some clinical trials will ask for them, and so in those scenarios I'll do one before I'm putting someone on treatment, but it's generally not terribly helpful to make the diagnosis or decide on somebody who's going to go on a watch and wait strategy.

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Thank you.

01:06:48.000 --> 01:06:51.000
Question for Christina. Someone writes...

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what heart issue did Christina experience, and what medication does she take?

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Oh, yes, thank you for asking. What it ended up being is endothelial cell damage in my coronary artery…

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and it was causing heart flutters and some light abnormalities, and they were able to isolate it during an angiogram, and they were very excited that…

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the heart itself was in great condition, which they had observed at that time. And I'm taking amlodipine and a little bit of metoprolol, but very, very low dose of both…

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and it's fine, it's great.

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And Dr. Burke, can you comment on which of the current CLL medications are more heart-friendly, let's say, compared to ibrutinib?

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Yeah, so ibrutinib is in the category of drugs called BTK inhibitors and its cardiac risks include what's called atrial fibrillation, which is an arrhythmia…

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and less commonly, ventricular arrhythmias, which can be more serious. And so that's the primary concern with the category of drugs called BTK inhibitors. The other two covalent BTK inhibitors on the market are acalabrutinib and zanubrutinib.

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Those also have some cardiac risks, but the risks with those drugs are less than those seen with ibrutinib. And then the non-covalent BTK inhibitor called pirtobrutinib…

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probably has very little cardiac risk. I personally can't tell, you know, whether patients getting treated with pirtobrutinib have a higher risk than the general population. Atrial fibrillation is common even in the general population as we get older.

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So, if there is a risk with pirtobrutinib, it's very low. So that's a heart-friendly medicine, and then venetoclax and the CD20 antibodies, obinutuzumab and rituximab, are drugs commonly used in CLL, have very little cardiac risk, if any, so those are safe for the heart.

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Is pirtobrutinib approved for frontline treatment?

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Pirtobrutinib is not approved for frontline treatment. There were data about using pirtobrutinib in frontline presented at the annual meeting of the American Society of Hematology or ASH…

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five months ago, in December of 2025. So, it is conceivable to me that it will become approved as a frontline therapy, but as of today, it is not approved.

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Would that be your go-to if it were or when it does become approved for frontline?

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Not necessarily because…

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there's several sort of cautions about that. Number one, people might still like fixed duration therapy, single agent pirtobrutinib would be continuous therapy. Number two, we don't really know how well some of the other BTK inhibitors, like acalabrutinib and zanubrutinib might work after pirtobrutinib.

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Whereas we know that pirtobrutinib can work quite well in patients whose CLL has progressed after acalabrutinib and zanubrutinib. So, is it a one-way street or a two-way street? We're not so sure. So, there are some, you know, unknowns about using it in the frontlines.

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It may become an option, but I wouldn't say it would be sort of the only option we would think about as standard therapy for initial therapy for CLL.

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I think somewhere in the list of questions I saw someone ask about…

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limited, you know, fixed-duration treatment versus continuous treatment. I'm confused about that. I, I don't, you know, I assume that everyone would benefit from combination treatment, but that's not always the case, so can you explain…

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who are candidates for one treatment approach versus the other?

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Yeah, I mean, I think everyone is a candidate for either one. The only biological feature of the CLL, well, let me back, that's an oversimplification, there are some biological features of CLL that could cause…

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one to think about one strategy versus another.

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We think that patients with the highest risk CLL, which is those who have deletion of chromosome 17P or a TP53 mutation...

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benefit in terms of so-called progression-free survival, which is how long your CLL stays in remission from continuous therapy as opposed to fixed duration therapy.

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That doesn't necessarily mean that you live longer if you get continuous therapy, it just means your CLL stays in remission for longer. So that is one scenario where most experts will advise continuous therapy with a BTK inhibitor…

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ss opposed to fixed duration for one year, although it's with that caveat that we don't truly know the impact on overall survival.

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Another scenario in which one might think about not necessarily continuous therapy, but so-called MRD driven therapy, which is therapy the duration of which depends on how long it takes the CLL to go into…

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undetectable MRD state, as Christina was talking about with her own care. And that's the unmutated IGHV risk factor that I said earlier that we look at. There is a study called FLAIR…

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that was presented and published last year that suggested that patients with that unmutated IGHV benefit from the MRD-driven combination approach…

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as compared with single agent ibrutinib given as continuous therapy. So that's a nuance of choosing therapy that might lead one to, say, go with an MRD-driven strategy. It doesn't mean that that's…

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that you can't that you have to do that strategy. There are many people with unmutated IGHV who don't get that strategy, but that's a new nuance that we learned about in CLL last year that could be a factor in making the decision.

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On the other hand, you know, progression-free survival in the long run might turn out to be better with continuous therapy. There was a study last year called CLL17 that showed that at three years, it doesn't really matter in terms of progression-free survival whether you get continuous therapy or fixed duration therapy…

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but we don't necessarily know that that's true at seven, eight, nine, 10 years. So, there could be some potential advantages to continuous therapy. So, it's complex. It's not a one size fits all answer and this is why shared decision-making is so important.

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I was just going to say that very point, the shared decision point.

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Someone asks, as a person with CLL, what other types of cancers should I be looking out for? What type of non-CLL-specific care should I be requesting from my PCP or other specialist doctors to help ensure that I have…

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the healthiest path going forward?

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Yeah, great question. I think we do know that patients with CLL are at higher risk of getting other cancers.

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And the most common of those is skin cancer, particularly squamous cell and basal cell carcinoma, but it has also been reported in retrospective studies that CLL patients are at higher risk of other solid tumors, like lung cancer and colon cancer.

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And some patients with CLL who've previously been treated with chemotherapy like cyclophosphamide are at higher risk for bone marrow diseases called myelodysplastic syndrome and acute myeloid leukemia. So that's kind of, there's a spectrum of other malignancies that CLL patients may be…

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at risk for. How should that affect your life, and what should you do differently, is the next part of your question. And my answer to patients is really twofold. Number one, get your regular cancer screening that you're supposed to be doing anyway, age-appropriate cancer screening evaluation, such as…

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colonoscopies, if you're a smoker, CT screening for lung cancer is standard now, you know, and mammograms and all those types of things. The regular age-appropriate cancer screening. And number two, if you're not already doing it, I think it's a good idea for CLL patients to see a dermatologist…

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once or twice per year to get a good skin cancer screening evaluation. I have a lot of patients where they get picked up with skin cancer by doing that, and it's good to nip those in the bud and treat them before they become a problem.

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Thank you.

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Question for Christina.

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Which support programs, including expert advice, are available to people in Canada?

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Well, I believe it's the same. We do have a CLL Canada…

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site. So as far as I know, I don't have a lot of experience with it. I'm not from Canada…

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but I do know that there is a CLL Canada.

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Yeah, I think I don't think that Expert Access Program is available to people outside of the United States. I don't know if that's changed.

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So, I would encourage people to go on our website and dig for that information. As far as the other support programs, I don't think there's any geographical…

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restrictions, but…

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that information will be up on our website.

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I used HealthUnlocked. HealthUnlocked is a worldwide support group and it's mostly patients. There are several moderators involved that closely watch the feed. They are unbelievably informed. One of them, I believe is a bioresearcher.

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The patients are from all over the world. They will talk about the programs that are available in their countries and they share a lot of information. And the only thing I noticed as a younger patient…

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on that site, there were some things that might have been a little bit too forward, scared me a little bit. People are very, very open and honest. And so, when you look at the information, you know, make sure that you discern…

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what is real and what isn't. It's just members and patients talking. But I found it very helpful. It was very informative.

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Yeah.

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I've heard, I've not been on HealthUnlocked, though I've heard many good things about it. But it is a reminder that…

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information you get from the CLL Society is all medically curated, which may not be the case on HealthUnlocked. It's certainly not on the Facebook CLL support group, which I have not been to in ages. And just to follow up on…

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our Expert Access Program, it is not available in Canada...

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that comes to me from our official channels.

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Let's see.

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Somebody writes, oh, you know, Dr. Burke, can you…

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talk about clonoSEQ…

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and you can maybe address that as far as, you know how we determine MRD status, what MRD status stands for?

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Yes.

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And it's, you know, like becoming more universally…

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applied, or is it still sort of for those in the know?

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Yeah, so let's start with the basics of MRD means minimal or measurable residual disease. And it's a…

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method for measuring very small amounts of CLL. If you think about how do you measure whether somebody has CLL? Well, you can do a blood count, the same kind you get when you go to your doctor…

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and that tells you if you have a high lymphocyte count or not, but you can have a normal lymphocyte count and yet have half of those lymphocytes be cancer cells and you don't know it just by looking at the lymphocyte count, because they look just like cancer, just like normal lymphocytes.

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So, the whole idea is, can we be a little bit more sensitive in how we measure whether somebody has CLL if they have a normal lymphocyte count, can we, how low can we get if it's 1one out of 10 cells as a cancer cell, is it one out of 100? Is it one out of 1,000, or is it one out of a million?

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And so that's what MRD is measuring, and there are several techniques by which one can measure MRD. The oldest one is called flow cytometry, and it's kind of a fancy version of flow cytometry that is able to measure one cell, cancer cell out of about 10,000.

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And then you haveclonoSEQ which is a brand name for another technique to measure MRD that has the capability of measuring about one cell out of a million. So, you can…

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if you're going to do the clonoSEQ test, you have to do it, you have to get a baseline analysis when the patient has…

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active CLL with plenty of cancer cells in their blood or their bone marrow, and you identify a genetic sequence that's unique to their cancer cells, but that's not present in their normal cells. So, you identify the sequence...

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you treat the CLL, CLL goes away, and you're in remission.

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And then you can run a test on the blood or the bone marrow to say, do we find this genetic sequence still in the body? And if so, how many cells is it in? And the answer can range from…

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we don't detect it at all, and we analyzes three million cells. That's true undetectable MRD. Or we find, let's say, 100 cells out of a million…

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which is the same as one out of 10,000 cells with MRD. And the word undetectable really doesn't mean much. It, you know, it depends on how you define undetectable. Is it less than one cell out of 10,000, less than one cell out of one cell out of 100,000?

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Those are common sort of definitions for undetectable MRD. So that's what clonoSEQ is. It's a branded test for MRD, and it can be applied. It's not the only way of measuring MRD. Is it used by those in the know or by everybody?

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I mean, I think it depends and it's a little debatable how often should it be used and does everybody need it? I use it myself quite a lot, but I think many doctors in practice don't use it all that much and I think it's becoming more and more…

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utilized as a technique to understand where patients are, but there is some debate out there about, do you really need it or, you know, certainly you can treat CLL without it. And so, it'd be something to talk to your doctor about as to whether it's a test you want to have done for yourself.

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And who is, you know, UMRD can be a little bit complicated, because you can be undetectable measurable residual disease at the flow cytometry level but not UMRD at the clonoSEQ level…

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so, just another little wrinkle.

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Correct. So, the flow cytometry can only detect one cell out of 10,000. So, if you have, you know, let's say five cells out of 100,000 or 0.5 out of 10,000, the flow cytometry would miss…

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that, but the clonoSEQ technology would pick that up. So, is that undetectable? It just depends on how you define the word undetectable.

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Stephen, can I follow up on that?

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Sure.

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So, my specialist, we sat down and talked about it at the end of treatment and we opted not to do the clonoSEQ test…

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since the flow cytometry came in great.

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He asked my opinion, do you want to have that done? And I said, should I? And he said, if I were you, I probably wouldn't.

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If there was one little cell out there that you might just fixate and worry about that one forever.

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And I thought, you know, he has a point, so I opted not to do it. And I had questioned over the years, was it the right decision? I think it was, and I recently had a member in my Portland support group that did the cloneSEQ test...

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found four cells out of a million, and that person was upset. And so, you know, it could be a personal decision as well.

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Christina, you just beautifully described a shared decision-making process that you went through with your physician. That's exactly how it should be done.

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Thank you. Appreciate it, Dr. Burke.

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And just to make it complicated, you know my doctor…

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never suggested it.

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And three years after treatment, you know, I…

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got hip to clonoSEQ and requested it and had it done, and I've had it done every year since. And I can see the count going up…

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but it doesn't really, I mean, I know I still have CLL cells, but just to have even more fun and just to bring AI into it, I've uploaded my clonoSEQ results to ChatGPT and it's predicted,

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for what it's worth, that I'll stop, probably still be in remission for maybe another seven to 10 years based on the trend that it's increasing. Of course, take that, you know, with a grain of salt. But, ah...

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but I have fun with it. I don't I don't really get wigged out over lab results anymore. I've been doing this for too long.

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Yeah, well, Stephen, just to build on that, if you think about it, to have visible CLL, the sort of conventional old-fashioned definition of recurrent CLLs, you have to have a blood lymphocyte count greater than 5,000…

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malignant cells per microliter of blood. So, you probably have to have about half of your cells have to be, half of your white cells have to be malignant. So that's one out of two. So, you know, if you're at, if you're at one out of two, that's probably when you can just first start detecting…

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the CLL by a regular CBC that you get at your doctor's office. So, if you're at one out of 1,000 or one out of a 10,000, you're probably a long way from one out of two, and you can, if you could look at the slope of that curve, if you've had a bunch of these done…

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and just kind of calculate the, how long it's going to take you to get to one out of 2 or so. So..

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related to that, when people get diagnosed, they often think that I must have just gotten CLL within the last year…

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but…

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it's quite possible, given that it goes from one cell to two cells to four cells to eight cells, et cetera, et cetera, you may have had CLL for years, maybe even a decade prior to it being discoverable from a routine…

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CBC test. Is that a fair…

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statement?

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Absolutely right. I said before that the most common question I get is, Doc, what at what white count do you treat my CLL? Tied for that as the most common question I get in the clinic is, Doc, how long have I had this? And the answer is…

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probably a long time. It starts as one cell, and by the time you see it on a CBC, you have millions, if not billions of cancer cells in your body, and how long did it take to get from one cancer cell to billions…

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is probably a very long time, so it probably started a long time ago for most people, and admittedly, CLL, like most cancers, is variable in its growth rate. It is not the same from person A to person B. Some people, CLL moves more quickly, others more slowly…

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probably largely driven by the biology, the gene mutations that are inside that cancer cell causing those cells to reproduce. So, it's going to be different for different people, the rate of growth, but for anybody from the day it started as one cancer cell to the day you find it when it's billions of cancer cells, probably took a long time.

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Someone writes, how many second opinions should you consider getting? I got one immediately, but two years later I'm wondering if I should get another?

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And I guess it's not a second opinion if you've gotten multiples of them, but we'll just call them second opinions.

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Yeah, Christina, I don't know your opinion on this. I think it just depends. It's variable from one person to the next. Some people don't really feel the need for a second opinion. They're very comfortable with their doctor, they're getting great advice, and…

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they're happy with their care. Others really, it's really important to get that second opinion. And for some it's important to get a third or a fourth opinion and it's just sort of a personal preference. So, I would…

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don't, I guess my take-home point here would be, if your doctor's taking offense to your getting a second opinion, then the problem is with the doctor, not you. It is a good idea if you think it's right for you to kind of get that second opinion to learn more. There can be a challenge, which I failed to mention in my talk earlier, which was...

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you know, sometimes a second opinion differs from your first opinion, and then you can be a little bit stuck on, well, who's right? You know, I really like my first doctor, but my second doctor told me something different, and that might be a classic scenario where you say, well, I'm going to go get a third opinion. And, you know, in addition to doing your own research and all the other ways you can educate yourself. So…

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there certainly is room for third and fourth opinions, and it's, but that would be one scenario where I think it probably does make some sense, and it just, I would say it's just a comfort level thing.

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I agree.

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Dr. Burke, when especially when new patients come in...

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you know, they can get overwhelmed with all of the details and they can sort of just go numb. Do you encourage patients to record your consultations?

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Yes, I do. You know...

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or, you know, because sometimes people like, I don't know if the doctor was going to be offended if I were, they don't want to ask if they can record a question they think it's, you know, they're tapping into classified information.

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I don't know why a Doc would get offended by that. You know, can never predict everyone, but there's really no reason to get offended. You know, the CLL Society, Christina, you showed the slide where your CLL team includes a notetaker. Notetaking is great, but…

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if you have a recording of the conversation, you can go back and take notes on it a couple times through. And so, I think it's great to record it.

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And it serves as a resource that you can go back to later on and take some notes, and you might pick up some pearls that you missed the first time around. So, yeah, I think it's great.

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I used to bring a little GoPro to my appointments.

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Little camera.

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Someone writes, how do I communicate with my oncologist, hematologist that I would like a second opinion from an expert without offending them?

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So...

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yeah, as I said, if they're offended, they shouldn't be. So, I encourage it if my patients ask me that question. And so, number one, they may be able to help you choose someone. That is, if somebody comes to me and…

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says, I want a second opinion, I would say, well, great. Can I help you? And because I know who knows CLL and I know who's good at CLL, and I know who I might go to if I wanted an opinion about treating my CLL. So...

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I think your doctors can and should try to be helpful in, you know, aligning you with getting a second opinion that fits your needs.

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So that would be my suggestion that you do that. I always find it kind of odd, and this happens, where I find out that somebody's in the doctor's office getting a second opinion and they didn't ask me first, you know, and that's fine. I get it. Clearly, that person was worried about offending me or something…

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but I don't think you should be. I would be open about it if I were the patient.

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Can I add to that?

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Yeah.

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The...

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we have members in our group that we're in a very large state and there's not always specialists that are available close by. And some of the members, they very much enjoy their hematologists or they feel trusting in their care.

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And so, just because you go and get a second opinion, it doesn't mean that you're changing your care to that physician. And many of our members have that expert as a consulting physician to their hematologist.

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Well, just to say that's a very important role that CLL experts play. And that expert might be...

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you know, if you want to go to a different State and get on a plane and fly three hours. You can do that. It's probably not something you're going to be doing every week or every month.

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So absolutely, experts can play that very role in kind of helping you make those big decisions at those big forks in the road where you have to decide what treatment am I going to get. You make that decision with the help of that expert, and then you…

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execute that decision with your local doctor. That's a great way to use second and third opinions. So...

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Dr. Burke, this is probably going to be the last question. In an earlier CLL Society webinar on shared decision-making, Dr. Brian Kaufman described CLL treatment as a kind of long-term chess game…

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not just choosing the best therapy today, but thinking several moves ahead.

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Given that most patients aren't CLL chess grandmasters, how do you help them understand and participate in those longer-term strategic decisions…

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without overwhelming them?

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Let me start by saying I love the analogy because…

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I think it's very accurate. That is, when you make a move in chess…

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you are kind of making an educated guess as to what your opponent might do next, but you don't really know, and your opponent may surprise you and do something different. And I think CLL is…

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the same way, so that while you do make decisions and you, let's say you're choosing a first-line therapy...

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Ii's a question I get a lot from patients, and I love the question, which is, okay, if I choose this first line therapy…

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what are going to be my options as my second-line therapy when the CLL comes back, because we've talked about this disease tends to come back.

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And going back to that slide, I said, well, if you got treatment A, then your options are going to be XYZ for treatment B, and if you got, you know, treatment…

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different treatment as your initial therapy. Well, you're going to have some slightly different options as your next line of therapy. So, I think it's important to think those through. That's a, can make a big difference in choosing fixed duration versus continuous therapy, for example.

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And it's an excellent question to ask. It's an excellent question to think about and to kind of have some tentative plans for what you might do in the second line when it comes to that.

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So that's what I think, and I think your doctor can kind of help guide you to the answer to that question because it could affect what you choose to do now as you think about what are my options down the line after that.

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Thank you.

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Christina and Dr. Burke, any closing thoughts before we end today's webinar?

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Christina.

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Oh, well.

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My closing thoughts would be to…

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do everything to advocate for yourself. If you're unable to, hopefully you have someone that can help advocate for you.

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It's very important for you to be involved and understand what is happening with your health.

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And there might be times that you have to push a little bit harder with...

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you know, medical situations where you do advocate for yourself.

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And…

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it's definitely a marathon, not a sprint.

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Thank you. Dr. Burke?

01:36:35.000 --> 01:36:51.000
Yeah, I just I would thank everyone for your attention today. I hope this has been a valuable session for everyone and that you've picked up some good tips. My take-home suggestions for the patients in the audience would be…

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the same as Christina, really to educate yourself as much as you can about the disease to help yourself make informed decisions, to use your provider and all the resources we've discussed...

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those from the CLL Society, those from your support group, those from the Internet and AI. There are all kinds of ways that we can all be educated about this disease and others. And that could really help you make the best decisions on your…

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own behalf, and so thanks for your attention today.

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Thank you both. And I'll just remind everybody that…

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our Expert Access on Demand is a tremendous resource.

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So, we'd like to thank our generous donors and grant support from AstraZeneca, BeOne and Lilly for making this event possible.

01:37:52.000 --> 01:38:05.000
Thanks to all of you for joining us today, and a big thank you to our speakers for their participation in this program. Please complete our event survey and provide your feedback to help us plan for future events.

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This webinar was recorded and will be available on our website along with a slide deck and a written transcript of the webinar.

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If your question was not answered, please send it to trustedcare@cllsociety.org.

01:38:19.000 --> 01:38:28.000
Join us for our next virtual event, Ask Me Anything, featuring Dr. Joanna Rhodes and patient advocate Jeff Folloder.

01:38:28.000 --> 01:38:36.000
Please remember, the CLL Society is invested in your long life, and you can invest in the long life of CLL Society by supporting our work.

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Be strong. We're all in this together.

01:38:40.000 --> 01:38:46.000

Thank you so much.