Virtual Event Transcript
Ask Me Anything Featuring Dr. Joanna Rhodes and Jeff Folloder
July 15, 2026

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Hello, I'm Jeff Folloder, a longtime CLL patient and patient advocate. As a matter of fact, I'm now in year 17 of living well with CLL.

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Welcome…

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to CLL Society's Ask Me Anything where we spend the next 60 minutes answering your questions with a CLL expert, and we are so lucky to have Dr. Joanna Rhodes joining us today.

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There are no presentations and we encourage you to ask your questions via Zoom.

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This event is dedicated to your questions, so ask them early to make sure we try to get to them all.

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Before we begin, I have an important disclaimer to share. Nothing said today should be taken as medical advice. It's really, really important, any questions about your health and treatment should be discussed with your healthcare provider.

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So, without further ado, Dr. Rhodes, would you please introduce yourself to our audience.

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Hi, everyone. It's so nice to be with you, Jeff, today to answer all of your questions. My name is Dr. Joanna Rhodes. I am the Director of Lymphoma at Rutgers Cancer

Institute, New Brunswick, New Jersey, as well as Assistant Head of Lymphoma for RWJ Barnabas across the state of New Jersey. I'm super excited to be here. Thank you again to the CLL Society for the invitation…

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to come and chat with everybody about your questions, your concerns. Jeff and I were talking earlier during our tech check about what an exciting time it is in the CLL community for all of the research that has been going on for the past three plus decades.

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And how we're really seeing so much of the benefit from everybody's participation and trust in all of us in clinical trials and in research. So again, thank you all for your participation.

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Fantastic. We have a bunch of questions, and I'm really thrilled to see this group of questions because although some of them have been the same since I started my journey with CLL, a lot of them are new and really exciting.

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I'm going to start off with one question that seems to always pop up. It's about the way CLL is described. And the question starts off like this, I have CLL,..

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my doctor said it's the best cancer to get and not a big deal.

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So, should I still go to appointments and pay out-of-pocket expenses for blood work, imaging, and all those appointments?

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What's going on?

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This is a really great question. So, I take care of CLL and several other lymphomas that people also will describe as like a good disease to have. I am not of that mindset. I think that CLL is a cancer. It is a serious diagnosis. And while it may not require treatment right away,..

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it does require long-term monitoring to ensure that we are taking the best care of you.

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Even if you're not on treatment for your CLL, CLL is still there, and it can have some other side effects. So, one of the most important things that we talk about in visits are that CLL patients are at a higher risk for secondary malignancies or other types of cancers.

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That is most commonly non-melanoma skin cancers like basal cell and squamous cell carcinomas. And I think it's super important to be mindful of that and remember that it's not just your CLL that needs monitoring, but that you also have to undergo your routine healthcare maintenance, looking for…

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things like breast cancer, colon cancer, prostate cancer. If you are a smoker following the guideline or were a smoker and meet the guidelines, getting your routine CT chest either with your primary care doctor or pulmonologist to ensure that we are looking for early detection, early diagnosis of lung cancers.

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So, it's not just CLL itself that we're monitoring for. Seeing a dermatologist once, at a minimum once a year, is one of the things that I recommend for all of my patients.

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The other thing that…

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is a concern for CLL patients are other types of infections, so we know that CLL is a cancer of the immune system, and so the CLL cells themselves are our B cells, and the way that I really like to describe the immune system itself is it's kind of like the Department of Defense. There are different cells that do different jobs, that go to different levels of school…

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in order to be able to protect us from things foreign, like bacteria and viruses and fungus, as well as things domestic, like cancers. And so that foreign portion is really when we're thinking about the risk of infections that are associated with CLL. And again, CLL is a cancer of B cells whose ultimate job is to make antibodies to protect us from infections-

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But we also know that CLL causes some T-cell dysfunction. Our T-cells, I think people have heard about because these are the cells that get infected with HIV. And when you

don't have enough of them around, that's actually what defines AIDS. And as we know from our clinical experience and history with AIDS, those are patients,..

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you know, that have a higher risk of rare atypical infections as well as rare atypical types of cancers. And so our T-cells are like the generals of our immune system. They're really important for telling all of our cells what to do and where to go and when, and so you have this also underlying immune dysfunction with the generals of your immune system, with your T-cells, that puts you at risk for infections and other kinds of cancers,..

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as well as this intrinsic issue with your B cells, because that is the CLL cell. And so, the other thing that we talk a lot about in clinic and I talk about very extensively with my patients is the risk of infection. And so, the other portion that comes up with this is looking to see…

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how many infections are you having in a year? Are they all your usual once a year cold that you get every year, every December that you've had since you were 22, and that's just part of who you are? Or are these, you know, if sinus infections or upper respiratory tract infections that are lingering,..

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maybe you went to the ER for one, maybe you even got admitted for a pneumonia and ended up requiring IV antibiotics. All of those things come into play when I'm thinking about what is the infection risk for a patient, and that often can change over time depending on how long you've had CLL, or maybe even if you're on treatment for CLL.

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So, I would say I think it is an important diagnosis to monitor and to stay on top of seeing your oncologist or hematologist as well as your primary care physician.

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And I guess what I would add to that is there is no such thing as good cancer.

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Agreed.

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Cancer is cancer, and you should treat it seriously.

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You talked about surveillance and some of the things that you like to keep an eye on. And many CLL patients are familiar with this concept of watch and wait, or as patients like to call it, watch and worry. I think the in vogue term for it now is…

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active surveillance - find whatever we're going to call it. There's a period of time where CLL patients show up regularly to doctor visits…

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they get their blood test done, they get their lymph nodes poked on.

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What are the criteria that you as a doctor, what are the criteria that you are using to figure out when it's time to move from watch and wait…

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to treatment?

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This is a great question. So there actually are international guidelines from the International Working Group of CLL. Most recently, they were updated in 2018, although there's a yearly update that comes out if there's anything new that's changed.

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But it's consensus guidelines amongst CLL experts as to when are the, when is the time to start CLL-directed therapy. So by the current guidelines, those include developing lymph nodes that are bulky or painful or in a place that perhaps if they get much larger, could cause problem with an organ or organ damage.

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It has to do with constitutional symptoms, things like what we call our B symptoms, fevers, chills, night sweats, weight loss.

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We know that CLL can involve the spleen, and so sometimes your spleen can become very enlarged to the point where either it's painful or it's starting to affect your appetite and you're losing weight, and that's something new or maybe happening gradual over time, but it's becoming more bothersome.

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And then finally, we know that CLL affects the bone marrow and our blood cell production fact, which is our blood cell production factory. And so we know that it can cause anemia or low hemoglobin or thrombocytopenia or low platelets. There are specific numbers within the guidelines as to when to initiate treatment for those. A hemoglobin usually less than 10, and platelets less than 100, although I would say in clinical practice…

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if the platelets get to 99, it may not be that you have to start CLL-directed therapy the next day. And then the other one that can come up are fatigue and frequent infections. Those are the two that I think are a little bit challenging to sort of from a guideline perspective, say this is the exact time,..

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particularly in our day and age where everyone, it feels like is mostly fatigued on a day-to-day basis. And so, I think having a good working relationship with your hematologist, oncologist is so important because I might, you might say something to me that triggers in my brain,..

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hey, you're taking more naps, you're not doing the things that you're enjoying anymore because you're so fatigued.

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And maybe that would be a reason to start treatment at that time.

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Very good. So, since we're talking about starting treatment regarding first line therapies, are most patients now eligible for time limited treatment versus treat-to-progression? Is that the direction treatment is going, even for…

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IGHV unmutated status?

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Yeah, so I think that this is an outstanding question because as we pointed out, the CLL treatment landscape has changed dramatically in the United States over the last 10 years where we've mostly phased out chemo immunotherapy and have really focused on using our targeted agents that target…

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the way that CLL cells make more of themselves and stay alive too long, which is really the way that CLL comes about and continues on. The two major ways that we treat CLL

are either with this continuous therapy to prevent progression of disease and control your symptoms and control the CLL…

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versus these fixed duration regimens where you're on treatment for a finite treatment period, anywhere from one to two years, depending on the regimen and depending on the line of treatment. I think most patients are eligible for fixed duration treatment, even patients that are IGHV unmutated.

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We know when we look at the data from our, you know, very large pivotal clinical trials that maybe the patients who are IGHV mutated may have a shorter time that they are off of treatment, but the majority of patients still do quite well with these regimens.

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But I think it's a question to talk about with your physician of, well, with my disease biology and my disease markers,..

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can you guesstimate how long I might be able to stay off of therapy before I might need to start treatment again, or before maybe we see signs that the CLL has come back, but maybe puts me back in this watch and worry, watch and wait active surveillance mode.

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Again, because I think that that is a valuable piece of information to have when you're deciding between continuous therapy, which we know is so effective, as well as fixed duration therapy, which we also know is so effective.

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Very cool. I'm smiling right now because things have changed so much. I love hearing you say chemo has pretty much gone away, at least in North America, and we have all these cool options. So, let's have a look at a question that…

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one of our participants sent in. This patient was on fixed duration treatment with obinutuzumab and venetoclax,..

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this patient's in remission.

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Yeah.

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Hopefully for a really long time. I mean, that's what we all hope for.

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Here comes the hard question because we know that CLL doesn't always play nice.

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He asked, should I need treatment again? Can I have the same treatment or would an all oral fixed duration treatment be a good option?

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This is a great question, and this is, can I see into the future in 10 years, which is actually my favorite thing to do because I always like to think about, well, where do we think that the field is going? So, for the first portion of the question, yes, depending on the amount of time that you are off treatment.

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And in this treatment free period with treatment with venetoclax or obinutuzumab, retreatment with venetoclax obinutuzumab may be an option. There is actually a clinical trial that is looking to answer this question for patients that have been off treatment for one year or two years or longer.

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We know that it is an effective strategy. I think the better question is how long and what's the durability of that second remission, which is really what the trial is looking to answer. And we should have some of those answers in the next few years

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The challenge, of course, is when remissions are very long, it takes a long time for us to get data to tell you, you know, with a good amount of confidence as to this is what I think is going to happen. But it's a good problem to have in CLL, that it takes a little bit of time to get our definitive answers.

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I do think that the all oral doublets are very exciting. We know that we recently had the FDA approval for acalabrutinib and venetoclax for frontline treatment. And I do think that we're going to start to see more data for the all oral doublets in the second line and beyond setting, although that data, it does not exist currently in terms of an FDA approval, but would be a very reasonable option.

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There will likely be more options in the future. We now have BTK degraders that are under clinical study, and so we're really adding into what I call our CLL armamentarium.

And I do think that we'll see lots of different drugs and lots of different combinations under study.

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And in particular, answering this question of is there an optimal second line treatment for patients that got fixed duration therapy for the first time?

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Wow, I mean, it's a lot to take in. I'm going to press pause for just a moment, and I'm going to toss you a curveball.

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It occurs to me…

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that I remember my very first CLL doctor telling me, you take care of all the other stuff.

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Your family has a history of heart disease, so I want you to take care of your heart. I want you to keep your blood pressure under control. I want you to do this, that, the other thing, and he had this whole list of what is grossly called comorbidities. He says, you take care of those,..

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I'm going to take care of your CLL.

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And as I've aged and gotten older, of course, you know the body parts are wearing out, and things have to be done, and things have to be taken care of. And I find that CLL patients really do need to pay attention to the other things that are going on so that…

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care maintains a synergy. And this question came in on the Q&A line that took me by surprise.

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The question is, why are CLL patients with Alzheimer's…

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not eligible for Alzheimer effusion therapy? And I didn't even know that this was a thing.

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Okay.

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I will also say I know very little about Alzheimer's infusion therapy, so I am not sure to that answer. I am unfortunately a CLL specialist. But if you want to put the drug in the chat, I'm happy to try and look it up and come up with an answer on the fly while we're chatting during this webinar, because I'd love to be as helpful as possible.

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Sure.

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I will say that there, I do have CLL patients that have other medical issues and they have been told that they are not eligible for clinical trials, and that has more to do with regulatory issues than with you having CLL. I don't personally think it's fair, and I agree with you on that front.

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But I do think it is something that comes up, not infrequently, and it's something to chat with your doctors about. I recently had a patient who wanted to go on a clinical trial, I think actually was for an Alzheimer's drug, and I wrote a letter to the study section to try and see if I could help get him on.

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So, let's keep in mind the things that happen with all patients as they age. One of the most common things that shows up is, and I wish there was some deep bass notes in the background. Let's talk a little bit about osteoporosis – dun, dun, dun.

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Is there a correlation between CLL and osteoporosis?

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So, there's no specific correlation between osteoporosis itself, but there is a higher risk of fractures in CLL patients, what we call frailty fractures. This is very funny because this has come up recently, when I have been every year or so, I think about…

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what are the things that our CLL patients need, and what are the things that I should be doing and doing in conjunction with patients' primary care doctors? One of the things that we would recommend, there's no sort of blanket recommendation for DEXA scans for all CLL patients currently.

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That being said, I do think it is a reasonable thing to chat with your physician about because I do think that we do see these, you know, there's fractures in the spine, fractures in the hip that can be more closely associated with patients with CLL than not, and so I think it's something to be aware of.

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The other thing to discuss, and to, I think we talk a lot about vitamin D and vitamin D supplementation, it is very, it's always an in vogue, out-of-vogue thing. We talk about vitamin D supplementation as part of cancer treatments, both for, you know, solid tumor cancers as well as other…

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well as other issues. So. I think it is also a good idea to advocate to get vitamin D levels checked yearly and to make sure that they're replete. I think a vitamin D supplement is probably something that the majority of patients in the United States, given where our latitudes are and how much sunlight that we get,..

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it's probably reasonable to discuss with your primary care doctor. Additionally, there was a study that came out. It's, you know, just a data study, but it does seem that there is the potential that repleting a CLL patient's vitamin D that's on watch and wait, watch and wear active surveillance, ou pick your...

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your acronym, may actually delay time to first treatment. Now, a lot of these studies come with a lot of caveats, but vitamin D supplementation, when done in conjunction with your physician, I think is a relatively safe thing to do. And if you get derive that type of benefit…

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I think it's very much worthwhile.

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So let me ask a follow-up question. Because osteoporosis is a thing, and you mentioned frailty. For CLL patients, better to go to the Prolia route than the bisphosphonates route. Yes, no, maybe?

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I don't think that we know the answer to that. In other types of cancers, such as multiple myeloma, there's never been shown to be a difference in outcomes from a bone perspective for drugs like Zometa, which is a bisphosphonate in comparison to denosumab.

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So, I just don't think that we have the data to say in the CLL patient population that one is better than the other. They don't believe that that data exists for other tumor types as well as even within the osteoporosis landscape.

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So, I'm going to ask another, you know, hey, this is happening while CLL is happening.

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I can remember more than 16 years ago having my first CLL encounter at a Houston hospital. And one of the things the doctor recommended was that I see a dentist…

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more often.

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And I went, hmm.

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And two weeks later, I had a cardiology workup because I take care of that kind of stuff. And the cardiologist said the exact same thing.

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And I later learned that there's really good reasons why, but…

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is it important for CLL patients to stay on top of their dental health? And is there a link or just why is it important?

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Yeah, I think that this is a really interesting and important question. I do think it is important in particular for CLL patients to stay up to date on routine dental care. There's a slightly higher risk of periodontal disease in patients with CLL, and some of that might have, and then there's always this question of can you have,..

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you know, leukemic infiltration of your gums, a little bit more rare in CLL than in other types of leukemia. CLL patients, of course, have this underlying immune dysfunction. Can that potentially lead to issues with periodontal issues and dental abscesses and caries, potentially, as well?

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So, there's a couple of multifactorial reasons why dental care is so important. And sometimes that does just have to do with going to the dentist more frequently as well. I would say that even, you know, the periodontal disease world is one of these areas I think that's so gray and I, having been…

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targeted by many an ad for things that help with periodontal disease, even myself, I think it's an area of very large interest and one that I think we'll need to explore more in CLL too.

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Sounds good. Here's a great question. There's been a lot of discussion around uMRD testing, especially in limited duration treatments like venetoclax. What about continuous treatments with something like acalabrutinib?

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Is there any benefit to uMRD testing other than peace of mind, even if there is remission, would it make sense to stop treatment if there's no side effects? There's a whole lot to unpack there. Let's start with what is uMRD?

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Oh, yes, I was going to say this is a great question, and I think probably the hottest topic, I would say in CLL currently is what is uMRD? So uMRD stands for undetectable, we use measurable residual disease, which is a little bit different than what some of our colleagues use, which is minimal.

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But basically what we're doing is there's different types of tests that we can do on blood, on lymph nodes, or in your bone marrow to look to see at a level past what we can see, you know, underneath the microscope and even sort of the routine things that we do to diagnose CLL in a lab,..

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look at a very small molecular level, anywhere from 1 in 100,000 cells to one in a million cells, one in 10 million cells. So, to see is there one CLL cell amongst that whole amount of cells? Because we know that CLL, even if you're in a remission, there's still always the chance that it could come back in the future.

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The idea behind uMRD really is a deeper remission, the most important thing in order to prevent to prolong your lifespan. That's really the big question. In CLL so far, we have not we have not always shown,..

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depending on the treatment subtype that uMRD is the most important endpoint to achieve in terms of disease response in order to ensure that our treatments are working well. We had brought up FCR or chemo immunotherapy, in that era…

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uMRD really was prognostic, meaning it could tell us that people, how somebody would do long-term from their CLL treatment and what the likelihood was that potentially their CLL may never come back.

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In the era of the continuous BTK inhibitors, these are given continuously, and what we do know over time is that after a year or two or three or four or five of a BTK inhibitor, and most of our data from this comes from ibrutinib, which we use a little bit less of in the United States now,..

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we could still find CLL, but patients were doing very well. They had complete resolution of their elevated white blood cell count, their hemoglobin and platelets were normal, they had no discernibly enlarged lymph nodes, either on exam or even on CAT scans.

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Their spleen had gone back down to a normal size, but we could still find a little bit of CLL in there, and it didn't change how well people did and how long those remissions lasted with these drugs, which is why we don't really use this as our major metric.

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It is a little bit different with venetoclax and venetoclax-based regimens. So, what we do know is that for our fixed duration regimens, that if at the end of whatever treatment it is, because there's so many different options now, and depending on the type of test as well, because there's so many tests,..

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depending on that response that your uMRD response can predict how long it is before your CLL could potentially come back, where we know that patients with venetoclax-based regimens do seem to have a longer time off of treatment than those whose CLL does not get into an undetectable…

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disease state.

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That being said, we have not as a CLL community, decided that this is the utmost importance of getting to uMRD. And I do think that it's a good question to bring up with your doctor of, is this the right test for me? Should this be the goal of my treatment? Do I want to be want to see uMRD or not?

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If yes, why? If no, why? And then kind of tailor treatment from there, you know, in the next few years we'll be seeing a lot of data coming out looking at what we call these MRD-driven strategies where we really are treating to the point where patients CLL becomes uMRD.

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And then we'll see how well, and then we'll see in the context of a clinical trial, you know, how well patients do, how long those remissions last, you know, what is, you know, how long are people living when we're actually using these as our sort of metrics moving forward.

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So that's sort of the quick and dirty about uMRD, and hopefully that was,..

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a good enough answer.

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I think that helps quite a bit. I have noticed that there is an elephant in the room. So, I'm going to go ahead and ask you a question that is almost always on people's minds.

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With the kind of sort of diminishing severity of COVID.

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Yes.

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What's the current recommendation for COVID vaccinations? All of the COVID protocols specifically for CLL patients?

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This is a very hard question, and I think it's one that's very challenging. I actually became an attending physician during the first year of the COVID-19 pandemic, so I completely understand and appreciate and worked at a hospital that was one of the hardest hit in the United States.

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So, I completely understand and appreciate where that comes from, because in the in early 2020 and into 2020 '21, we're very much recommending that patients really kind of shelter in place, always wear a mask, don't eat indoors. I think now that the severity of COVID-19…

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symptoms, if you do happen to contract COVID-19, are so much different than it was in the earlier days during actually the height of the pandemic. I do think that…

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going back to sort of more usual life is probably okay for the majority of patients, so again, there may be some scenarios that are a little bit different depending on the type of treatment you've been on, whether or not you are currently on treatment, what your infection history is.

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That being said, because of this underlying…

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risk of infection that comes from the immune dysregulation, some of the immune compromise that CLL causes, I still do recommend patients stay up to date on COVID-19 vaccination. Currently, I believe the guidelines, because they do change a little bit frequently, is boosting every six months, which I am still recommending for my patients.

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Very good, very good. Well, it's not quite as bad as COVID, but one of the things that I hear quite frequently on CLL support group on Facebook is people complaining about colds and sinus infections.

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One of our participants asks, one, is this normal?

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Because my recent blood work shows my immune system is quite low even after remission. What's going on here?

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Great question. So, we know that there's sort of two, there are kind of two portions of our immune system. One is sort of this, what we call our innate immunity. So that's sort of the immune system that's there that's meant to fight infections. The second you get cut that…

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monitor for infections from things that we eat, that we breathe in. So, there's always sort of that, like, what I call frontline of defense. They're kind of like our infantry as part as like one portion of our immune system. The second portion of our immune system is something called the adaptive immune system, and that's really where our T and our B lymphocytes live in…

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because that's the portion of the immune system that learns. I call it going to, they all stay in school. But learning how to fight infections that you've seen again, that way you don't get as sick as you did the first time. That's why vaccines are so important. We kind of…

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decrease the severity of infections that you could potentially be exposed to if you are vaccinated previously.

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There's two portions of that. There's probably a component of looking at immunoglobulin levels in a CLL patient that's looking at, in particular, hypogammaglobulinemia. And so sometimes when that level is low, that can predispose you to get infections, particularly these upper respiratory tract infections and pneumonias…

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that can be, well, maybe not life-threatening, very bothersome and very terrible for quality of life to always feel like you can't breathe and you're always coughing and you're kind of tired, because when you have an infection, you never feel quite right.

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And then there's also probably a component of issues with cellular immunity that are probably a little bit less well studied and harder to discern in a regular primary care office or even in your CLL specialist office, because those are often things that allergist and immunologists are very much focused on and know how to test for better.

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I do think that one of the challenges for CLL patients is this immune dysregulation and this immune dysfunction that doesn't always get better just because you've gotten treatment. So, a few regimens have shown that maybe you can have some, what we call, immune reconstitution. Your immune system…

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healing itself and going back to normal by treating your CLL. Some of the fixed duration regimens have limited data for that in the setting of, again, testing that was done on clinical studies. And so, my recommendation there is, oh, I do think for patients that do have frequent infections is, one,..

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have your immunoglobulin levels checked, because I think that that's kind of like that first big step of, am I hypogammoglobulinemic or not? I would always make sure that you are seeing an ear, nose, and throat specialist, just to make sure that there isn't actually something structural, that is actually, can happen, whether you have CLL or not, and that can predispose you to get these infections that are harder to treat.

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And then I think the other question is, you know, what type of infection is it? Because sometimes there are things that can be viral infections, they can be bacterial. Very rarely you can get fungal infections that affect the sinuses. And so, I think that those are sort of the three things to look for.

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And then I think talking with your CLL specialist, primary care specialist about do you need to involve an infectious disease doctor as well is always a potential.

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Very, very good. We got a wonderful topic sent in from Richard. And it's actually very near and dear to my heart. Because of my family history of heart disease, I'm very concerned about what I may..

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be choosing to take when it's time for me to be treated again.

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Richard is talking about things like atrial fibrillation and its relationship to acalabrutinib and zanubrutinib and ibrutinib.

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Is there a cardiac concern with those drugs? If there is a cardiac concern,..

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what's the best route to take? Do we go Gen 1, Gen 2, Gen 3? And how do we ask for it?

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Great question. So, all of our BTK inhibitors have some cardiac side effects. That has to do with proteins that are expressed on the actual cardiac, what we call myocytes, so the muscle cells within your heart can actually express BTK…

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and other what we call kinases, sort of these proteins that are part of…

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the pathways that BTK inhibitors can kind of inhibit. There's…

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and so that's, it's one of these class effects of all the drug, of all of our BTK inhibitors. So to date, there has not been a single BTK inhibitor that has been tested or gone to market that has zero cardiac side effects.

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We do know that the second generation covalent BTK inhibitors like acalabrutinib and zanubrutinib, when they have been compared head-to-head, our first generation inhibitor, ibrutinib, they do have fewer cardiac side effects far and away. So less atrial fibrillation, less ventricular arrhythmias, which are the ones that are the really scary ones.

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And overall less hypertension, although zanubrutinib still has about a 25% risk of hypertension, whether that's new onset or worsening of the hypertension that you may have when you start a CLL treatment.

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I think one of the things that we're much better at doing now than we were doing when these drugs were first approved, you know, with ibrutinib back in 2014, is understanding these cardiac side effects and restratifying patients. I think that…

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for myself, for my own patients that are starting a BTK inhibitor, I always try and check an EKG before we start. I try and check an Echo, and for any patient that really has a lot of cardiac comorbid conditions, as you said, Jeff, I am trying to involve a cardiologist in my CLL patient's care. We have…

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a cardio-oncologist that I work closely with, a lot of large academic centers have these types of cardiologists now. It's sort of a burgeoning field in cardiology because so many of our cancer medications, whether it's BTK inhibitors or otherwise, can have cardiac side effects, and we know that.

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Obviously, cardiac issues are such an important side effect to manage and manage effectively. So, I think that there are ways to…

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mitigate the risk, and it's just making sure that we know what your risks are up front.

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So, I'll do a quick follow on because we talked about ibrutinib, acalabrutinib, zanubrutinib. What about the new bell at the ball, pirtobrutinib?

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She's a great drug. So pirtobrutinib is a little bit different than our other, than our first and second generation BTK inhibitors, because it does, it's what we call a non-covalent BTK inhibitor. So, our other BTK inhibitors bind to that protein, and then they don't let go,..

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they just stay there forever.

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Pirtobrutinib works a little bit differently in that it's noncovalent, so it binds but it doesn't stay on indefinitely, and so there's some different, and it was created for a very specific reason, and that was to actually overcome the resistance that can develop…

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for patients whose CLL has been treated in particular with ibrutinib, because of the years that these drugs were under development. So that was actually the reason that the drug was created was to overcome this resistance because we knew that BTK was such a wonderful target and so effective for patients with CLL in controlling their CLL.

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Pirtobrutinib also is a little bit different in that it's, we know, that all of our BTK inhibitors bind to that one protein, but they also can hit other areas. And so that can cause some of the side effects. And so that pirtobrutinib is also designed specifically to try and really only bind to BTK…

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and so that shows a little bit of differences in the side effect profiles. So, it is a little bit, I would say it's a different inhibitor, a little bit of a different drug than our sort of current first and second generation covalent inhibitors. It is a great drug and it has been FDA approved now since 2023 first for CLL that had had at least two prior lines of therapy…

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and most recently was updated to have had at least one prior line of therapy based off of some recent data that came out over the last six months. So, it is a great drug and a potential great treatment option for many patients.

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Fantastic. Jacob's got a question that I know…

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kicks around the back of a lot of CLL patient brains these days. A lot of these drugs have some phenomenally quick results. He talks about his white blood cell count going from 167…

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to 10…

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and our RBC going from 3.18 to 4.79 and his hemoglobin doubling from 7 to 14.

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Here's a question that gets asked all the time. Hey, things are going great. Can I cut back the dose?

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Excellent question. So, dose intensity can matter depending on the type of treatment that you're on. So, for there's data for venetoclax, obinutuzumab that shows that you really get the most…

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time off treatment and the deepest remissions, and there's no issue with efficacy as long as you can keep your venetoclax dose above 300 or above.

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Now people have side effects and they need to be mitigated in different ways, and so I think that the first question is always ensuring that, you know, a drug is as close to the optimal dose as possible, because there's, you know, pharmacologic reasons of wanting to be able to block the most BTK,..

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block the most amount of BCL2's in the case of venetoclax in order to be able to maximize our responses. With that, we know that not every person is the same, and so

tolerability of drugs is so important. I personally don't usually drop the drug dose if patients are doing well,..

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as long as their disease is responding. I dropped doses because patients are having issues with side effects. And in particular, I think this comes up most frequently, you know, with continuous BTK inhibitors, that over time…

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there are side effects that while they may again not be the life-threatening side effects that we talk about in conferences, are the ones that really affect patients' day-to-day life, the things like my muscles hurt, my joints hurt, I'm like nauseous a little bit after I take my medication,..

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maybe I have some diarrhea. I'm having a lot of bruising in cosmetic, and it's really bothersome. I really don't like having bruises, my arms look, you know, like I went, you know five rounds with Muhammad Ali. Those are sort of the side effects that I think are really important to talk about with your doctor because there are ways to potentially…

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dose modify certain medications to help with side effects, but I, in general don't change doses just for without like a good reason without an actual medical reason to do it just based off of how the clinical trials have been run.

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That seems fair and reasonable. I'm going to go back to the concept of watch and wait for just a little bit because we did receive two questions that pair well with the whole watch and wait paradigm.

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I find this to be an incredibly insightful question. Something that I hadn't considered myself. Is there long term harm…

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to the bone marrow and immune system in general, having untreated CLL for many years?

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I don't think we know the answer to that question. A lot of our early intervention studies have actually not looked at sort of answering that question of like, what is the infection risk, things of that nature from having long-term untreated CLL.

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But have more really looked at, are we, does treating CLL earlier make you live longer? Or does CLL, treating CLL earlier make a difference in terms of your lifespan? That's really what a lot of the current early intervention studies have looked at.

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Okay.

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I don't know the answer to that question, but I think it's a good one. I don't think that,..

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I think it's very challenging, because I think that there are CLL patients that we all have in our practices that are 25, 30 years on active surveillance and are doing really well and haven't had any complications from their CLL.

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And so it's hard to say that those are patients that would have derived benefit from treating their CLL at the time that were initially found, particularly given sort of what the available treatment options were then. But I think it's a very valid question of should,..

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what should our early intervention strategies look like moving forward?

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So earlier we talked about the need for data. And I know how important the data is to be able to answer these questions with authority. We need more data to figure out if some of CLL patients have actually been cured. We need more data to see if…

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this is the effective route. Are we doing any clinical trials or specific research on the benefits of…

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active surveillance versus just go ahead and treat it?

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Yeah, so this is a great plug for a study that just finished accrual that was run through the cooperative groups in the United States. So, there was a study that was just, we don't have any data from yet, but we should in the future looking at whether or not…

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treating patients who have high-risk CLL, so high risk by the CLL IPI, which is a prognostic tool that looks at several factors, including IGHV mutation and the presence or absence of deletion 17P or TP53. So, looking at some of our molecular markers, not just the clinical markers, the way that some of our old staging systems like…

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Rai Binet, the Rai and Binet staging systems, used to look to see if treating our patients who have, you know are high risk, treating them early so within 18 months of diagnosis versus treating them at the time that they have an IWCLL…

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criteria for treatment, if there's any differences in survival, and then looking at some of the other, what we call secondary endpoints, looking at some of the other things of importance, like infection risk, side effects related to treatment, things of that nature.

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Fantastic. Here's a straight up question. I remember when I first started this journey, I got my punch list of all the different things that I had, all the different doctors that I had to see to make sure…

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that secondary cancers didn't show up. You alluded to this earlier. What percentage of CLL patients have developed secondary cancers?

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So, it can be as it depends on the subtype of cancer, and I would say that for some cancers, we don't necessarily have as much robust data, but probably around 10 to 20% of patients can develop a secondary skin malignancy, most commonly basal or squamous cell carcinomas.

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So, the non-melanoma skin cancers, which is why I think it's so important to have those things checked out. But there is an increased risk of other types of cancers. I think we've seen lung cancer, breast cancer, GI cancer, sarcomas, things of that nature. So always, always important to stay up-to-date on routine healthcare maintenance.

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So, for the things that I always recommend is following, you know, the guidelines for your women for yearly mammogram, staying up to date on routine pap smears, those guidelines change a little bit. So, I think it's always important to have that conversation with your practitioner and reminding everybody that you are a CLL patient, so you are at slightly higher risk than some of the patients that,..

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you know, included in some of these pivotal studies on screening, staying up-to-date with your dermatologist going once a year, staying up-to-date on your colonoscopy, which I'm sorry, I know nobody likes to hear that one. It's the one my patients get mad at me the most for when I harp on it.

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I do recommend that all of my men get a PSA checked. That at one point was not, that guideline has shifted in different ways, but because of the inherent higher risk of getting other types of cancers for patients with CLL, I do recommend that. And then we now have…

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recommendations for screening for lung cancer, in particular for patients that have who are higher risk based off of smoking history, so definitely talking to your doctor about that and figuring out if that is something that you would potentially be eligible for.

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Okay, so let's forget about the fact that there's a couple of hundred people listening in on us right now. Just you and me talking, Dr. Rhodes, just you and me.

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Tell me about the one CLL clinical trial that excites you the most.

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Oh,..

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Oh,..

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this is hard.

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I've, so I am in the camp that I do think that MRD is an important endpoint for our patients treated in the frontline setting with fixed duration treatment. So, we are going to see a bunch of trials that I think are very interesting looking at consolidating these remissions. So, you're in a clinical, you finish your treatment,..

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you're in a clinical remission but your MRD positive and going on to receive some extra treatment to really deepen that response. There are varying ways to do this, and I think

we'll see, and I don't know, I don't know of the mechanism or the drug that we use to do it matters is more of the concept of this that I find very exciting.

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Because I think if we, as we talked about, the longer you go without needing treatment, the higher likelihood that our drugs will be better. And even if our drugs aren't better, we will 1,000% know how to use them better and manage the side effects better.

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And so I think that those are all things that are of great value, particularly thinking about future state of CLL care.

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That's very insightful. Earlier, we have talked about standards of care and how the standards of care has progressed over time.

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This is a very common lament.

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Patients find that there is so much variation among CLL doctors in deciding the when to treat, how to treat, how to respond to various lab numbers.

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If there are standards,..

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why do we get faced with such a wide range of opinions from CLL doctors?

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Great question. So, this is a great question, and I imagine if you put 12 CLL experts in a room, we would all have similar opinions, but with just a slight difference in our interpretation of data.

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I think one of the challenges is CLL is a rare disease. And so, when you look at a CLL clinical trial that's large and randomized, which is sort of our gold standard for how we change our standards of care,..

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they're much smaller than they would be for patients with breast cancer or prostate cancer, where there they're looking at thousands of patients at a time, and we're really, most of our large phase 3 clinical studies have about 400, 500, maybe 600 patients so,..

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we're looking at these things on a different scale. And I think the other challenge is that our care standards have changed so quickly over the last 10 years that when we look at some of our data as data comes out,..

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the what we call the control arms, which was sort of the care standard when the trial was written, that might actually be obsolete or something that we're not using anymore in routine clinical practice by the time the trial reads out. That's another difference. And I also think that there is something to be said about everybody's clinical experience with some of these newer agents as they come out.

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You kind of learn a feel for how to manage side effects a little bit differently depending on what the side effect is. And so, I think that that's also where some of the variation can come into play.

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The final, and I think one of the big things is that I think…

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a lot of what and when we're starting treatment and how we're managing a patient's side effect, a lot of that I think, does come from the doctor-patient relationship, and so I can think of a patient that I had whose labs, you know, did not look like they were by IWCLL criteria, you know,..

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did not require treatment, but the patient I knew well enough after having known them for several years to know that there was a very marked difference in his constitutional symptoms that were very clearly impacting his quality of life.

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And I knew that because I had been taking care of him for five years. And it may not have been something that even he would have signaled to another practitioner and it wasn't even like they had said that they wanted to start treatment. It was just that I knew that person so well that I knew that this was the time. And so I think that…

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even though we have number guidelines and things like that, it is a patient specific decision. And I think part of,..

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particularly when we're in the watch and wait, watch and worry active surveillance portion…

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of the CLL journey is finding the doctor that you trust to have these conversations with because…

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as I get to know a patient as a person, I get to really understand what the trajectory, what I'm looking for within their disease, even that I think is going to be the reason that they might need to start treatment or may need to stop treatment or may need to dose reduce treatment, things of that nature.

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It's very cool. While we have been doing this program, this Ask the Expert, we've been focusing on the CLL patient. And that is right and proper, but I always have a special place in my heart for…

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the caregivers of CLL patients.

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And we have a scenario that Sandy has offered.

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Okay.

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My mother was diagnosed three weeks ago and currently in watch and wait at 76 years of age.

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And to be frank, Sandy is extremely worried.

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She suspects that Mom had it for a few years.

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Sandy's really not understanding this whole watch and wait thing.

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Who's doing the watching, who's doing the waiting? Well, we know we're waiting. What are we? What's, what's being watched for?

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Sandy wants the best care for her Mom and Sandy's just not sure what questions to ask the doctor.

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Mom's currently seeing a hematologist.

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Absolutely.

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Should they go for a CLL specialist? I know that's a lot of questions in one scenario to unpack, but this is important stuff. The caregivers have a lot going on, and they may not know how to ask these questions.

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I completely understand and empathize with Sandy with the situation that you're in. It's very hard. So, one of the things that I think is very hard is this is one of the only times when we tell you that you have a cancer diagnosis that we are going to monitor.

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So really, we are undoing everything that we have always talked about in terms of proactive surveillance and finding a cancer early because intervening early will make you live longer. So, I think that that's the first very large kind of,..

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I call, it's wrapping your mind around something that doesn't make any sense. I have leukemia, and you're telling me I don't need to do anything right now. You are, doctor, you are crazy. You are absolutely crazy. That must be like, I must be the craziest person out there. And the reason is, is that we've never shown in any study,..

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however, it's been done thus far, that treating CLL at the exact time that we have diagnosed it will make you live longer.

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But I can tell you that when I treat something, when I find it, there is a likelihood to have side effects, and so,..

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one of the things that I'm, that we find not infrequently is that patients are fine, we're finding CLL much earlier now than we did probably 20 years ago, and that has to do, I

think, with the way that medicine has changed and the number of blood tests that we're doing…

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and that people and you know most commonly, very commonly, we're picking up CLL for patients that are going for routine surgeries and things like that. It's picked up on pre-op clearance, on insurance blood work. All of these things that come up.

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So the, I think that the big questions as a caregiver to ask about is one, making sure that…

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is the diagnosis correct? So, do we really have CLL? And can you explain to me how you know that this is CLL? I think that that's always knowing exactly what the diagnosis is, is the most important thing to get out of any visit with a hematologist oncologist.

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I think the second question is going through the different potential reasons that someone would need to start treatment for CLL.

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Big bulky lymph nodes that are painful, constitutional symptoms including fatigue, fevers, chills, night sweats, weight loss, and…

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is the spleen enlarged, any changes in appetite are what we call early satiety, eating less eating less in a sitting than you had previously, and then looking at the blood work and looking at anemia and thrombocytopenia, hemoglobin and platelets, and looking, and you can ask at every visit.

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You know, are any of these numbers different than they were the last visit, and if they are, are they different enough that that might require a change in our treatment and what we're doing in the watch and wait.

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I think that the other component of this is, of course, I like the way that the CLL Society does this is building your CLL team. And that team can really look like whatever it is that you want the team to look like. I think it is always a great idea to get a second opinion. I encourage patients to do it. I am the second opinion for many patients.

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So, I think if there's ever a question that you're just not sure if this is the right thing to do, always get a second opinion because all it's going to, all it does, is cause you a little bit more peace of mind that the treatment plan is correct and that more than one person is said to do the same thing…

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and I think that it's definitely worthwhile.

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Fantastic. Dr. Rhodes, this has been great.

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Thank you so much for joining us today.

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Before we close the program, do you have any closing thoughts for our audience?

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One, I just want to applaud everyone, thank you everyone for coming and your participation. It is very clear that you are all very well versed in CLL and some of the nuances that come into taking care of CLL patients and taking care of all of you.

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So, thank you for your participation. I hope that this was useful. I always learn something when I hear a patient ask a question, and it always gives me some ideas for some of the things that we really need to be looking at. So, some of the things that I'm going to remember, the question of what are sort of the long-term sequelae or consequences of having CLL for a long time and not treating it, I think that that's something that…

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we could potentially look at to answer one of those questions, because I think it's important. I would like to just say I think that this is from…

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a treating perspective, this is an exciting time because we do have so much to offer patients. But I also like to be mindful of the fact that CLL is a cancer diagnosis. I agree with Jeff. I don't like saying that, like, I don't think that there's a good cancer to have…

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but I do think it's one that we are able to manage and we have great treatment options for as well as lots of ongoing research. And I hope that you all have doctors that you

feel like are your partners in your CLL journey. And if you don't, I encourage you to continue to look for the person that you…

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feel will be your partner in this.

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Very, very well said, and we are very grateful for your participation. I know I am.

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I'd also like to thank everyone who joined us today. I'd also like to thank our generous donors to CLL Society and grant support from Genentech, Lily and BeOne for making this event possible.

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A few brief reminders, please, please complete the short event survey shared with everyone. We really want to hear your feedback and appreciate your time completing the survey. That survey is how we put these programs together and make them better.

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Please join us on July 22nd for our next webinar. It's got that sound in the background, Medicare Part D in 2026, what patients need to know.

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I know we weren't able to get to all of your questions. If your question was not answered today, please send it to our trusted care exchange email service. This is a free service available on the CLL Society website under Programs and Support.

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Please remember to follow CLL Society on Facebook and other social media platforms.

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Lastly, CLL society is invested in your long life and you can invest in the long life of the CLL Society by supporting our work.

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On behalf of Dr. Rhodes and myself,..

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thank you very much for joining us.