Facebook Live Event Transcript
Ask Me Anything – Featuring Dr. Lindsey Roeker and Jeff Folloder
May 23, 2025

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Hello, I am Jeff Folloder, a longtime CLL patient advocate.

Welcome to CLL Society's Facebook Live Event "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. Lindsey Roeker joining us today.

There are no presentations, and we encourage you to ask your questions on the Facebook page, if this is how you are joining us, or through the Zoom platform.

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

Before we begin, I have a few important disclaimers to share.

Nothing said today should be taken as medical advice, any questions about your health and treatment should be discussed with your healthcare provider.

The information that you post on Facebook will be shared on a public forum, so please do not post or share confidential information.

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And without further ado… without further ado, Dr. Roeker, would you please introduce yourself for our audience?

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Absolutely. Thanks so much for having me today. I'm Lindsey Roeker, I'm a CLL specialist and hematologist at the Mayo Clinic in Rochester, Minnesota, and I am thrilled to be here today to talk about your questions and make sure that we are all on the same page about our CLL journeys.

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Sounds fantastic. We already have a slew of questions, and I got to see some of these before the event started, and I'm cheering because I know these questions get asked all the time. Looking forward to having expert answers on these questions.

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We're going to start off with one that I think is really, really important. Many CLL patients get put into what we call watch and worry mode, what the medical community calls watch-and-wait mode.

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What are the criteria that are utilized and taken into consideration when determining if someone should start treatment?

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Yeah, this is a great question, and one that I spend a lot of time chatting with my patients about. So, there are five things that I'm looking for when I'm understanding whether somebody needs CLL-directed therapy.

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The first two are based on lab tests, so we get a CBC at each visit, and with that CBC, we're looking at hemoglobin…

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which is a measure of the red blood cells, that's the part of our blood that carries oxygen from our lungs to our other tissues, and we're looking at platelets, which are the part of our blood that helps us make blood clots if we're cut or have an injury.

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And we use cut-offs for these values, so a hemoglobin under 10, suggesting that a person has anemia, or a platelet count under 100, um, these are the cutoffs that we use to help us understand if we need to treat CLL.

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The next two are based on a physical exam. So, we look for big or bothersome lymph nodes...

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and we look for a big or bothersome spleen. Now, big, there are criteria that we have established in terms of what constitutes big, but bothersome is obviously subjective. So, we asked people about whether they're having any discomfort or pain in their lymph nodes, um, or if they're noticing quick growth in those lymph nodes or the spleen.

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For the spleen, the most common symptoms that have, um, come with that can be pain or discomfort under the ribs on the left side, or a sensation of belly fullness, and sometimes people describe early satiety, which means that you take a couple bites of food and you just don't feel hungry anymore.

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So those are all the symptoms that we're looking for when we're thinking about the spleen.

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And then the last is the most subjective, and this is CLL-related symptoms.

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So, we're looking for fevers that are unrelated to infection or other inflammatory things, um, so fevers, night, day after day that are really related to the CLL.

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Um, night sweats, where you're waking up drenched, having to change your pajamas. Again, night after night, not in the setting of an infection.

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And then the third is weight loss without trying, so any significant weight loss, definitely want to chat with your provider about.

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And those are the symptoms that we're looking for. And the reason that we, um, have patients enter this period of active observation, or watch and wait is because we've done experiments to look at whether treating early helps people live better or live longer.

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And we've done a number of these, um, experiments and haven't found that intervening early really helps people do better, um, and many people are able to do very well with observation.

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Now, all that being said, as you know, we have a lot of new medicines that work incredibly well for CLL and are less toxic than any of the treatments that we've ever had access to before, which is fantastic news.

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So, with that, as, um, kind of the background, there are ongoing experiments to look at whether treating with some of these less toxic, more effective agents early, um, could be helpful. So, there are studies, and most of them are designed specifically for people who have higher risk disease, where we think the risk or likelihood of needing therapy…

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is much higher. Um, so if this is something where you're in the newly diagnosed stage and someone has mentioned high-risk disease to you, if that is, you know, that early intervention strategy is of interest, there are ongoing clinical trials looking at that question.

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That's fantastic information, and I'm glad you brought up the subject of these new medicines. When I started, there weren't a whole lot of medicines. There were just a few, and the gold standard was FCR.

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Um, we're not in that world anymore, and I see a bunch of questions here.

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Mm-hmm.

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Asking about this brave new world, so let's start off with BTKs.

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I know that BTKs have been around for a bit and have shown a lot of really good work in the CLL arena.

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What's a BTK degrader? What's a BTK inhibitor? What's the difference in all of this stuff? And… what's their status?

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Absolutely. So, BTK is… Bruton tyrosine kinase. And this is a protein that's within the CLL cells, an enzyme, and basically what it does is it takes the signal from the B-cell receptor, and it takes it and amplifies that signal into the nucleus. So, it's sort of like a signal that's saying, grow, divide, grow, divide, and it's telling our cells…

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that they need to continue living and dividing, making copies of themselves. And this is what kind of turns the cancer cells on, if you will.

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So, it's actually that dependence on the B-cell receptor signaling from the outside of the cell to the nucleus, where we keep all of our genetic information, and it's that um, that transfer of that signal from the outside to the nucleus that goes through BTK.

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So, it's almost like a speaker. It takes a quiet little, um,..

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or an amplifier, it takes a quiet little signal, and it makes it loud so that the inside of the cell knows to grow, divide, grow, divide.

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BTK inhibitors have really revolutionized the treatment of CLL. So, these are medicines that are incredibly effective with very high response rates. And right now, we have covalent BTK inhibitors, and we have non-covalent BTK inhibitors approved for the use in CLL.

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Covalent BTK inhibitors are ibrutinib, which was the first one developed and approved, then we have acalabrutinib, and we have zanubrutinib. These are all approved drugs for the treatment of CLL…

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both as a first treatment, as well as, um, in later lines of therapy.

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And covalent BTK inhibitors go in and attach to BTK, and basically shut off that signaling, so that the signal from the outside of the cell into the nucleus is no longer happening. It's basically telling the cells to chill out.

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You don't have to grow, you don't have to divide, you can just kind of lay low.

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It moves the cancer cells out of their microenvironment into the blood, where they kind of live out a lifespan and then die off. So, the goal of this therapy is not to kill off every CLL cell in the body. The goal is really to just get everything to kind of…

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calm down, is how I think about it. So those are covalent BTK inhibitors. In terms of recent developments, we have now seen the approval of pirobrutinib, which is a non-covalent BTK inhibitor.

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And this drug was specifically designed, um, as a BTK inhibitor that would work when covalent BTK inhibitors have stopped working. We know that one of the ways that um, CLL cells can outsmart covalent BTK inhibitors, like ibrutinib, acalabrutinib, and zanubrutinib, is by basically changing…

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the shape of the hook point where the drug goes in and hooks onto BTK.

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So, picture this as a key that's going into a lock. One way to get the key to stop working is by changing the configuration of the lock, right? Then, all of a sudden, your key doesn't open your door.

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So, um, one way that these CLL cells outsmart these drugs is by changing the shape of BTK. And non-covalent BTK inhibitors have been developed to work even when the shape of BTK is changing.

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So, um, that is, that's a new class of medicines that have been approved for CLL when other medicines have stopped working. Um, and specifically, the approved drug is pirtobrutinib.

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Now, BTK degraders are a new class of medicine that are being studied and in early phase clinical trials moving into later phase clinical trials, and we can talk about what that means. But these are medicines being developed because they're able to go into the cell, basically hook onto the BTK and make the cell eat it up so that we don't have BTK in it...

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anymore. So, in that situation, rather than just telling the BT, you know, stopping the BTK from working, so you no longer have that amplification process. Here, you're just entirely getting rid of BTK. So,..

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three different classes of medicines, all working on the BTK pathway...

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to kind of, um, help the cells stop growing and dividing the way that they're programmed to.

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That is amazing stuff, and… I think I'm actually understanding how they work a little bit better. Um, it was suggested for me that pirtobrutinib might be a good choice.

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And one of the reasons I was given was that there was an extensive history of heart disease in my family, and that pirtobrutinib has a very low incidence of cardiac side effects. So, I know that there are so many things that CLL specialists…

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have to bear in mind when choosing these drugs. So, I've got a question for you.

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These sound fantastic, should we use these things by themselves? Should we use them as combination therapies?

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How do we figure out who gets what?

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Yeah, great question. So, for most people, when we're thinking about the first treatment for CLL, the decision making is between BTK inhibitor...

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continuous therapies, meaning you're on these medicines for as long as they're working…

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or fixed duration therapies. And the FDA-approved option is the combination of venetoclax and obinutuzumab that's given as a combination of pill and IV treatments that are used for a year and then stopped.

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Um, we additionally just got data on the combination of acalabrutinib, so taking the pill from the first combination, and venetoclax, taking the pill from the second combination...

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um, and using those in combination for a first treatment of CLL. That's now in the NCCN guidelines but is not yet FDA approved. So, um, we have a lot of good options. And in terms of figuring out what option is best for each person,..

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I think there are a couple of things to consider. The first is...

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there's underlying disease biology, meaning that there are genetic features of the disease that suggest kind of how it's going to respond to different therapies, and that's a really important consideration as your doctor is thinking about what treatment might be best.

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The second piece is what other medical problems does a person have? So, for, um, people who have a lot of history of heart disease,..

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BTK inhibitors might be a less good choice, whereas for people with significant renal disease or, um, uh,..

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that's kind of one that comes to mind, venetoclax might be a little bit more challenging. So, using those other medical problems to help us decide if one of these approaches is safer is another strategy.

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And then, if there are no strong, um, indications in those two pieces, meaning disease biology and comorbidities or other medical problems, that's pointing us one direction or the other,..

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I spend a lot of time talking to my patients about preference, because these are very different approaches.

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BTK inhibitors are pills that you're on for as long as they're working.

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They are typically fairly easy to start, so the monitoring required is relatively less,..

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um, but they're medicines that you have to be on for the long term, whereas venetoclax and obinutuzumab and acalabrutinib and venetoclax are therapies that really, um, require a lot more monitoring in the beginning and a lot more visits. So, for some people...

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that's, um, worth, worth it, because you're on therapy for a year and then you stop. And for some people,..

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the idea of getting into clinic once or twice a week for many weeks in a row is just a total non-starter. So, um, patient preference is a huge piece of how we make decisions. And in terms of deciding on combinations...

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versus continued monotherapy, it's kind of those pieces. It's what, what does the disease look like?

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What are the other medical problems? And what does a person want to do, um, how do they want to spend their time?

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You snuck in that phrase that so many of us are arching our eyebrows at right now -

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time-limited treatment. How do people get to a choice of, okay, you're going to take this…

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for a year, or two years, and then you're going to be done?

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How do we get to that?

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Um, so the, these therapies have been studied, the venetoclax-based therapies have been studied that way. Um, and as we were talking about BTK inhibitors, the idea here is they go into cells and then tell them to kind of stop growing, stop dividing. Venetoclax, on the other hand, is…

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a medicine that goes in and flips a kill switch within the cancer cells.

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So it's basically, um, it's a BCL2 inhibitor, it goes in, and it gives the signal…

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that the cell should basically undergo apoptosis, which means break open, explode.

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So, the goal there is really deep remissions, where we're getting rid of the cancer cells. And with those venetoclax-based approaches,..

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many people are able to, um, eradicate their CLL to a level that we call undetectable MRD, meaning that with really fancy technologies that we use to look for any residual cells, we're not seeing any there.

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So, venetoclax-based approaches have been studied as time-limited therapies because the goal is to get rid of the disease...

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deeply and quickly, and then have a period of time afterward where patients are not requiring therapy.

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Now, with the current medicines we have, we, um, we usually, we're not talking about cure, so we don't think that we're able to get CLL to a point where there is no chance that it will ever come back.

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For many people, this is a disease where, in the future, it does end up coming back, but then the idea is we have strategies for managing it down the road as well.

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So, let's talk about numbers. CLL patients love to have definitive evidence that this is working.

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Mm-hmm.

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Is it common for white blood cell counts to drop significantly, say, within a week of beginning an obinutuzumab treatment?

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Yeah, so obinutuzumab is a CD20 monoclonal antibody. It's an immunotherapy that's given by IV, and it goes in and the medicine hooks onto the CLL cells, and it brings our immune system in to get rid of them, to clean them up.

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Um, it's an incredibly effective drug at clearing the peripheral blood for many people, so it's a medicine that goes in and really does clear out that disease very quickly. Um, it is common that we see that within that first week of treatment…

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white counts can drop very significantly and people can even develop low blood counts with obinutuzumab therapy.

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Now, obinutuzumab has been studied in combination with venetoclax as a one-year treatment. So despite that quick early response,..

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Um, we still encourage kind of that one year of therapy in combination with venetoclax, because um, because that extended, you know, exposure is needed to really get rid of the disease in all of the spots, not just the peripheral blood, um, at one point in time.

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So, I've got a follow-up on this, this particular question. Does that white blood cell count crash indicate that the patient is going into remission? How do you define what remission is?

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Yeah, so there are IWCLL criteria to define remission and we look at a number of things. So, it's do we normalize the lymphocyte count? So, lymphocytes, um, in the, in a blood test are, it's a look at the bucket of cells that contains the normal part of our immune system, and then if there are CLL cells in there, they're counted in the lymphocyte count as well.

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So, we look for a normalization of a lymphocyte count. We look for reduction in size in the lymph nodes and in the spleen, and in order to say that a person has achieved a complete response, we look for, kind of,..

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those levels to be normal. So, normal lymph node size, normal spleen size and then we also look for improvement in the other hematologic parameters. So, we want to see a normal hemoglobin, a normal platelet count,..

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um, if those were low before. And then in order to define a true complete response, that also requires a bone marrow evaluation to say, okay, by an eye test, so a pathologist looking at a bone marrow under a microscope,..

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we don't see any CLL cells here, and those are the parameters that we use to help us understand. And then the last piece is also…

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kind of absence of symptoms. So, we think about these fevers and night sweats and weight loss, and we want to make sure that those are all gone, um, to call a patient truly in remission.

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Gotcha. Um, let's look at a particular treatment combo: obinutuzumab plus venetoclax.

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Patient has gone through that program, and they have attained full remission.

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You mentioned this MRD negative testing. This particular patient had the MRD6 testing.

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Um, one, what is MRD6 testing and how often is it going to have to be done?

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Is there something that would indicate the need to do it again?

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Yeah. So, MRD is minimal residual disease, and we have a couple of mechanisms for testing minimal residual disease.

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So, there's something called flow cytometry, which is basically a fancy cell sorting test. We look for the markers on the surface of the cells, and we sort them into buckets, and we say, are there any cells in the CLL bucket?

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So, that's flow cytometry. Historically, that has had a sensitivity of 1 times 10 to the negative 4, and that has historically been used to define undetectable MRD.

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We now have more advanced methods for testing MRD that are called next-generation sequencing.

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And this is a test where we look at the barcode of the cells at the start…

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and we specifically look at the IGHV mutational sequence. So, we're looking at what does a CLL cell in this person look like at the beginning?

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And then we take a blood sample later and we scan it for one in a million cells. So that's the 1 in 10 to the minus 6 sensitivity. So U-MRD6 usually means that you can't find one in a million cells while looking for this barcode that was defined before.

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Now, um, yeah.

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Please, please tell me, I hate to interrupt, but please tell me that there's not some lab tech looking at these cells one by one by one by one. A million is a lot!

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These are all, um, kind of advanced, um, processing kind of tests where, um, there are publicly, you know, they're, um, available tests like clonoSEQ through the adaptive platform. There's also, um, kind of homegrown, uh, looks at next-generation sequencing at academic centers, and,

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and looking at, kind of, with big data, um, analyses, can we find any of these cells?

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S, that's kind of the process for looking for undetectable MRD.

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And MRD is a really interesting study, because there have been studies, so this kind of dates back to the chemoimmunotherapy era, now, as we've talked about, we're not using chemoimmunotherapy anymore, but when patients were treated with chemoimmunotherapy,

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we knew that if patients achieved these deep responses, undetectable MRD, their disease stayed in remission, on average, longer than the people who didn't achieve that deep response.

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It's kind of like, think of it like a garden. If you have a bunch of weeds and you cut them all off at the stems,..

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they'll come back faster than if you really pull out the roots, right? So, you're, like, getting that deep response by, by getting the roots out and looking at whether that's occurred.

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This was then studied with venetoclax-based regimens. So, with the combination of venetoclax and rituximab in the relapse refractory setting, that was the Murano study,..

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or venetoclax and obinutuzumab in the frontline study, and then in subsequent looks at, um, venetoclax-based therapies, we've seen that MRD does predict progression-free survival, meaning that people that achieve those deep responses have their remissions last, on average, longer than the people who don't achieve those deep responses.

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So, we know that it has prognostic value. There are studies looking at whether we can use MRD as an endpoint to guide treatment duration, meaning not only are we looking at whether you know, if you achieved this endpoint, what happens in the future but can we actually…

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adapt therapy based on achieving that endpoint? And the studies and data are all, um, kind of in the early phases and immature.

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So, as of right now, if you're using venetoclax with obinutuzumab...

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that's a fixed one-year duration therapy, meaning you get it for a year, and then it stops, regardless of MRD status,..

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there are limited data to say that doing anything outside of that is the right thing to be doing.

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Um, so right now, I really think of MRD as being a research test and a prognostic test…

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rather than one that needs to be performed. So, if you got Ven-Obin, and you're like, nobody has ever tested my MRD status,..

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that is not wrong, by any means, um, so I want to reassure the people who are in that boat.

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And the second is, we don't know, really, at this point, what to do with those, with that information.

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There have not been any data saying that retreating based on a change in MRD status is the right thing to do. Um, and for many people, there is a significant lag between when they turn, when they develop detectable MRD and when they need therapy.

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When we looked at the people treated in MURANO, again, that was venetoclax and rituximab in the relapse refractory setting, so people who had had prior therapies for their CLL and then were treated with venetoclax and rituximab,..

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we saw that the time between MRD conversion, meaning going from undetectable MRD to positive, until they needed therapy, was almost half a year.

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So, um, and there's a lot of variability there, for some people, it's much longer, for some people, it's shorter.

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So, if you're a person who, um, you know, prognostic testing really appeals to you, and you are able to use it to help with planning and things like that,..

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um, I talk to my patients about the value of that.

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But I also think that there's a possibility that for some people, that causes a lot of anxiety without actionable information so, I think that, um, being realistic about, like, what are you doing with this information, and is it going to be helpful to you, or is it going to be harmful…

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is a real thing and worth talking to your doctor about.

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So, I hate to break this to you, there is an 800-pound gorilla that has walked into my office.

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And that gorilla has a name, and that name is fatigue.

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Fatigue is something that a lot of CLL patients talk about, complain about.

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They know it's real, if only to them. Can you provide some background on your current knowledge of cancer-related fatigue? People want to know, what are the factors?

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Yeah.

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Uh, what are the issues that are causing it? But most importantly, what are the ways to minimize this fatigue?

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Yep. So, fatigue is a really interesting and tricky symptom, because there are so many things that contribute to our energy level.

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So, I think of our energy level as being like a bucket, and a lot of things are willing to take ladles of water out of our bucket to leave us empty and feeling fatigued.

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There's the element of the cancer cells themselves, and there are, um, you know, secretion of enzymes and different signaling,

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chemicals in our body that can drive fatigue. There are treatment-related effects, so people on therapy, some of those therapies can drive fatigue.

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There's also the emotional factors that are real, um, in terms of um, this is a disease that, for many people comes with emotional consequences, and I talk to my patients about this a lot. This is normal.

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And also, doesn't have to be the case, because it's hard to have a new diagnosis, and that understandably drives anxiety, and also we have tools for that, so, so that's one plug.

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And then there are other pieces, so there's, um, anemia, which can cause fatigue in and of itself.

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There are other medical problems, so those comorbidities that we talked about can certainly drive fatigue. And then there are, in some cases, vitamin deficiencies as well that can cause…

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issues. So, it's multifactorial, meaning there are a lot of contributors here.

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And you want to do everything you can to make sure that you're kind of addressing each of these pieces. So um, from the cancer therapy approach, we are doing a lot of experiments, like we talked about in the beginning, to see if…

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treating early helps people live better, live longer, those kind of things. That's one possible strategy.

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The other, um, and then treatment is also another piece, because a lot of people talk to me about, like,..

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gosh, I'm pretty tired, but when we look, there really are not a lot of other indicators that therapy is warranted in this case, and because treatment can also cause fatigue, it's a hard symptom to try to target with CLL-directed therapy…

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um, and one that doesn't always get better with therapy. So instead, we often talk about what other things can we do to support you and support, um, your energy levels…

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without kind of touching the cancer part of it. Um, some things have actually been shown to be very helpful. So, exercise is probably the single most important thing that we can do in order to bolster our energy levels.

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I talk to people a lot about strategies for, kind of, often people will say,..

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gosh, fatigue always strikes in the middle of the afternoon. It's 3 o'clock, where I just feel like I'm laid out and can't do anything.

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We talk about, like, let's time exercise so that you get the adrenaline boost right before that fatigue is going to...

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set in, so let's go out for a brisk walk, get some sunshine on your eyeballs at 2.30, if 3 o'clock is the witching hour.

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Um, so that's one strategy. Nutrition in general, I think, is fairly poorly understood and fairly poorly studied within cancer. I think we're working on and doing a lot to understand, kind of, um,..

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what the ideal diet is for people with CLL and other blood cancers, but as of right now, the data are limited.

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Now, we all know that what we eat actually impacts how we feel, and I think that that's a universal human thing that we can acknowledge.

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Um, in terms of the diet that probably has the best data overall, the Mediterranean diet is one that's been shown to help people, um, significantly, especially from a cardiovascular risk perspective. So, thinking about fruits, vegetables, lean proteins, and olive oil rather than animal fats is kind of, if you're looking to make modifications to your diet, probably a place to start. And hopefully in the future, this will be an area where we learn a lot more and learn about what actually is the best diet for people with CLL.

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Um, and then the other things that I'll plug are, um, if you really are having a lot of fatigue, talking to your doctor so that they can look for other medical problems that might be going on.

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Thyroid dysfunction, diabetes, uncontrolled high blood pressure, those can all definitely can cause fatigue.

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And then sleep apnea is another, um, big one, so sleep apnea is fairly common and undertreated.

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So, um, you know, chatting with your doctor about what other things could we be missing that are contributing to my fatigue is, is an important piece.

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Indeed, um, I'll repeat what my wife has continued to tell me.

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And, uh…

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eat less, eat better. Exercise more.

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And that's the, that's the end of her lecture, and apparently, she knows a couple of things.

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Um, while we're on the subject of this fatigue, it's real.

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I know that CLL patients, in general, are classified as immune compromised, or immunocompromised.

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So, we have a little bit more to worry about, and that worry, as you said, can contribute to the fatigue Let's talk about COVID. How often should CLL patients be getting a COVID booster? And then after that, what else should we be getting vaccines for?

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Great questions. So, um, we know that the risk of infection and serious infections, meaning ones that land people in the hospital, is an excess risk for people with CLL. So the best tools we have to protect against that are vaccines.

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Um, so I ask everybody to get a flu shot once a year.

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Stay up-to-date on the CDC recommendations for COVID vaccines, so you can actually check that out on the CDC website, and it goes through, like, based on which ones you've had before, which ones are indicated.

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Um, and then I ask everybody to be up-to-date on their pneumonia vaccines. There was a relatively recent approval of two new ones that are called PCV20 and PCV21.

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So, if you haven't had those, um, it's worth chatting with your doctor about whether that would be indicated.

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We talk about the shingles vaccine, and specifically the vaccine is called Shingrix.

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It's a series of two vaccines that help protect you from shingles. Shingles is a bummer, so it's nice to prevent it if you can.

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And then the last is RSV vaccines, if you're of the age where that's indicated.

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Um, these are kind of the vaccines that we know can, um, improve outcomes.

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There are, um, live virus vaccines are available in general, and those should be avoided in people with CLL, because there have been cases of people actually getting sick from those live virus vaccines.

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I've recently had a bunch of people ask me about the measles outbreaks and cases of measles that have been occurring.

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Unfortunately, we don't have a measles vaccine that is not live, so MMR is not a good vaccine for people with CLL.

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Um, so in general, kind of the, the standard precautions of hand washing, staying away from people that are sick, um, are kind of the right strategies for that, and while measles cases are obviously very scary, and we're all hearing about them, um, they're still relatively rare, and there's, we're, we also have a lot of people with herd immunity, meaning…

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that a lot of people have been vaccinated against measles, so it's less likely to spread like wildfire through the population.

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This is really, really good information. Let's bounce around a little bit. Let's say that patient, one of our patients, has gone through a treatment regimen.

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And it really, in my mind, doesn't matter which regimen they've gone through.

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All of these have some side effects, whether they're minimal, whether they're moderate, whether they're severe, and intense.

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After stopping treatment, how long should those side effects continue?

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Especially bone pain.

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Yeah, um, so, most of these medicines wash out of our bodies fairly quickly.

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Um, meaning that the, um, the medicine is actually isn't in your system after a few weeks. So, a lot of the side effects related to these therapies should mitigate fairly quickly. If you're having symptoms that are lasting, um,..

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much longer than a few weeks to a few months, certainly, it's worth talking to your doctor about that to make sure that there isn't something else going on that's driving those symptoms.

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Bone pain is one that's kind of interesting. I saw that, um, come up as a question.

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Because a lot of our therapies, we actually don't think of necessarily causing bone pain.

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Now, muscle pain or joint pain, sure, but, but bone pain is a little bit less common, so chatting with your doctor to just make sure that nothing else is going on, or that you're not missing something for that is, is a reasonable thing to do.

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Great. Let's stick around with some of these, uh, maladies that occur for CLL patients.

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Um, in managing one of the larger Facebook CLL groups, there are two complaints that come up over and over and over again, and I'm kind of curious, especially since we've got some blurbs in the questions about this.

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Is post-nasal drip and sinus issues, are these a CLL thing? I hear these all the time.

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Yeah, so a couple of things, um, post-nasal drip and sinus infection, so, sinus infections, um, are more common in people who have CLL.

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And it's worth checking immunoglobulin levels in that situation, so CLL can drive low immunoglobulins.

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Immunoglobulins are the protein part of our immune system that's sort of like our first line of defense as we're exposed to stuff. Helps our immune system recognize and fight off infections early.

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If your levels are really, really low, there are tools called IVIG, or intravenous immunoglobulin...

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where you get, um, kind of a cocktail of immunoglobulins that help protect you from infections. And if you have low immunoglobulins...

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that IVIG can actually be really significantly helpful for some people...

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at reducing the severity, duration of infection, and frequency of infection, especially for sinus infections.

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So, um, if that's a symptom that you're dealing with, it's worth chatting with your provider about whether you're immunoglobulin levels are low.

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Please, please take a sip of that water.

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I apologize. Um, yeah, but the next piece is that, um,..

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post-nasal drip, super common whether or not you have CLL. So, there are some people who can have, actually, CLL infiltration into their sinuses?

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I'm sorry. And if you are having a lot of post-nasal drip, it is worth kind of talking to your doctor about it to figure out what's going on there.

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Fantastic. Go ahead, grab some more water. Um, I'm going to tee up a couple of more issues that CLL patients frankly, complain about.

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One, urinary tract infections. A lot of people say, I'm getting them all the time. Is it, is it recommended that these patients take antibiotics every day for UTIs?

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Great question. Um, it kind of depends on the pathogens that are being found, so it's worth chatting with a urologist for this.

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There are some people who have colonization and they actually have bacteria in their urine all the time, but it's not actually causing inflammation. That's a different situation than people who are having, like…

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urinary tract infections kind of in isolated incidences, and a conversation between urology and your oncologist can be really helpful to figure out the best strategy for managing that.

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So, what about back and leg pain? Is that a CLL thing?

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Great question. Again, back pain, super common, unfortunately. Um, the reasons that CLL can drive back pain…

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can be enlargement of the lymph nodes, especially in the retroperitoneum, which is the area around the spine.

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So, if you are having a lot of back pain, or, or pain that's wrapping around your body, kind of that sensation of a hug of pain, um, that's definitely worth chatting with your doc about and seeing if there's some imaging that might be done to…

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make sure that there aren't lymph nodes interfering with the nerves around the spine.

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Um, earlier in the program, you mentioned something about lymph nodes, and when they get bigger, you know, are they hurting? Are they impinging?

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Um, this patient tells us, they were diagnosed with CLL, SLL last month after experiencing pain in my armpit and shoulder.

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A self-exam revealed a lump about mid-armpit. Doctor found a lump near the base of my breast. The pain bothered me for about two weeks and then receded….

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as did the swelling. Both have come back recently, and this time the pain radiated not only in my shoulder…

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but partway down my arm and into my shoulder blade. My doctor says that inflamed lymph nodes don't hurt.

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I've got pain. Could they be pressing against some nerves when they get inflamed?

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Yeah, yeah, so, so sometimes these lymph nodes are just in bad spots.

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Um, and in this case, it sounds like maybe there's a lymph node that is near, kind of, the nerve that's, that's going to the areas that are described in terms of having pain. Now, this kind of waxing and waning, like, it was big, then it was small, now it's big again;..

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um, there are a couple things to think about there. The first is, some people have this with vaccines, so, like, when they get a vaccine in this arm, they get kind of transient swelling in their arms, so that

would be something I would ask this person about, is, like, was there any, was there any trigger where all of a sudden you had this enlargement?

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The other thing that can happen is infections on the arm, um, can kind of drain into that armpit…

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basin, lymph node basin, and you can see enlargement transiently. There are also some people that, right at the beginning of their disease state kind of have this rapid growth that then plateaus.

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I always talk to people about we really don't know what exact, what path we're going to be on until we watch it for a while, because for some people,..

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um, either white count growth or lymph node growth can kind of be on a linear path.

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For some people, it can kind of go to a level and then plateau off, and for some people, it waxes and wanes.

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Um, and, and each of those pathways is normal, it's just we don't know which one we're going to, which roller coaster we're on until we are on it…

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for a while. Um, so in that case, it sounds like that lymph node is probably messing with some of the nerves that are innervating the arm and the shoulder and all those things, so probably some imaging to make sure that we know what's going on, and if it's really persistent, thinking about that as an indication for therapy is probably a reasonable strategy.

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That's really, really good insight. I find this next question to be really, really interesting, because it's something that I had not considered before.

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Is memory loss common in CLL patients?

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Great question. This is actually something that we're actively working on in terms of research question.

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There have been some associations with heart disease and dementia and things like this, so, um, we're, it's still an area that we're exploring, um, in general.

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CLL tends to be a disease that's often diagnosed in older people, so the average age at diagnosis is 72. Obviously, there's a really wide range, so people are in their 20s and 30s at diagnosis, people are in their 100s when they're dealing with CLL, so it's a, it spans the spectrum but,

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if you are noticing concerns about memory loss, it's probably not, it's not a clear association where there's been a lot of data to say that that's the case, but it's definitely something that's being explored and worth chatting with your team about in terms of,

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first of all, making sure that you're not missing any infectious things, so, if you've had a history of a lot of treatment…

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with an immune system that's been compromised for a long time, there is an increased risk of some infections that can affect the brain, so making sure that that's not going on is always really important.

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Um, and then also, if there's kind of the more common version of memory loss,..

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connecting with neurology to see if there are strategies for slowing that down can also be helpful.

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I love this conversation that we're having. These are genuine questions that people have, and this is actionable information, if you will. I'm sorry, lawyers, I didn't mean to sound legal there.

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Um, people want to know how to deal with the stuff that matters to them, so we're not talking in these big, giant, broad...

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paint strokes here, we're actually helping people with the things that matter to them.

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Earlier, you mentioned that you're looking at the platelet counts. The, you know, are they normal? Are they low? Are they really low?

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One of the things that goes hand-in-hand with low platelets, unfortunately, is bruising, right?

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Do you have any recommendations, uh, for patients who are dealing with bruising? How did, how do you deal with it? This is not fun.

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Yeah. Totally. It's not fun at all.

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Um, if it's bruising, where it's black and blues, but not big pockets of blood,..

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one thing I talk to my patients about is, like, this is really annoying, and it's obnoxious, and I fully recognize that, and it's also probably not very dangerous,..

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um, in a lot of situations. So, there's that piece that sometimes can just provide peace of mind, that if your platelet count is looking okay, and um, you know, you're not showing evidence of disease progression, some of that bruising is…

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fairly common as we age. Um, part of it is that the connective tissue under our skin thins out with age…

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and bruising becomes more common because you actually just see the stuff that's always been happening, you're just seeing it more now.

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The other piece is CLL cells can secrete chemicals that make it more common to bruise.

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So, um, and then the last piece is that when blood deposits in the skin,..

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depending on skin type and all of these kind of things, there can be just basic, it's called hemosiderin deposition, but it's basically just, like, the dye from the red blood cells kind of seeps into the tissues and can leave long-lasting,..

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kind of color change in the skin. So, all of this being said, yes, it's more common in people who have CLL as well as people as they're aging. It's super annoying, I fully recognize that. And also, if your platelet count is okay,..

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it's not, and you're not getting these big bruises or bleeding other places, blood in your urine, blood in your stool, coughing up blood, throwing up blood,..

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blood, when you're brushing your teeth, it's not, um, it's not a dangerous thing.

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No, you just reminded me I have to make an appointment with my dentist. Great, great, great, great, we'll get all of that taken care of.

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Um, here's an interesting situation. How often do you recommend MRIs for CLL patients? What indicates the need for this test?

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Yeah.

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My doctor does an annual MRI, while other patients recommend only when needed. What's going on here?

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Yep, so the guidelines for CLL actually recommend against routine surveillance imaging.

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Meaning imaging that's not symptom-driven, it's just, like, by a calendar. Um, and the reason is that there's not with MRIs, but with CT scans, there's excess radiation exposure.

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And often, that MRI, unless you're watching something particular, isn't going to change management. Now, if you've had prior imaging where you have a really big lymph node and there's been growth, and your doctor is watching something specific, of course that's a totally different scenario.

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And then the other piece is if you are having symptoms that are driving the need for imaging, then that's also a totally different situation. But as a rule of thumb for people with CLL who are on active observation, asymptomatic,..

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and have not had any evidence of huge lymph nodes, there really is not a need for ongoing, yearly imaging or anything like that.

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That's, that's good information to have. Um, another 800-pound gorilla has entered my office.

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CLL patients are in an interesting role, and we often get told that we need to see the dermatologist at least every year to be surveilled. And for some of the, some of us, that's a surprise.

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Yep.

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Uh, can you report on stats that may reflect how likely CLL patients are to develop other cancers, especially skin cancers, after their CLL diagnosis?

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So, CLL impacts our immune system in a lot of different ways, and part of it is that those CLL cells actually directly interact with our normal immune cells and make them just less good at doing their job…

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which, that results in that increased risk of infection that we talked about earlier, and then also an increased risk of cancer.

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And depending on what study you look at, this can be anything from a 20% increased risk to an almost, you know, over two-fold increased risk, meaning that you're twice as likely as someone without CLL to get, these other cancers. So, non-melanoma skin cancers are particularly common in people with CLL, which is why we ask people to see dermatology regularly for full body skin checks.

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It's good to catch them when they're shallow and small, so that you don't need a ton of therapy for them, and that's why we ask people to see the doctor regularly.

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I also talk to my patients frequently about making sure that we're staying up-to-date on age-appropriate cancer screening, so we don't need to be doing extra stuff, but we should make sure that we're vigilant about the stuff we should be doing anyway.

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So, colonoscopies, when they're due, prostate cancer screening when it's due, uh, mammograms when they're due, pap smears when they're due. These are really important tests to help catch cancers early, or even in the case of colonoscopies, you know, catch precancerous processes that can turn into cancer down the road.

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So, um, important to stay up on all of those pieces.

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Good stuff, I'm going to give you a little bit of background here.

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Um, one of the questions came in, they say, they are on watch and worry and have experienced slower than normal recovery periods following two unrelated surgeries in the past year.

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Continued soft tissue issues after a total knee replacement, a year post-surgery. Retinal swelling after a cataract surgery in one eye that's taken over four months to resolve, causing blurred vision.

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And, quite frankly, has delayed the right eye surgery. Have there been any studies on how CLL affects the body's healing capabilities?

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So, there's a lot that we don't know about CLL, and things that we've observed clinically that we don't have a full understanding of kind of the physiologic underpinnings of why this is happening.

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Um, in this case, I would make sure that we're not missing infections, so with the, especially with the delayed healing after an orthopedic surgery, making sure that that's not an untreated infection, for the reasons that we talked about, right? There's an increased risk of infection with CLL, and…

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surgery puts people at risk for, for infection too. So, like, did we just see an infection there? But, um, I've had patients kind of report the same, that after surgeries, they're, they do have slow healing. It's not uniform, it's not everyone.

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Um, and we're still doing a lot of, um, kind of science to help us understand why this is happening.

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And it's a highlight that we know a lot, but we don't know, we also don't know a lot about CLL and, and kind of how it's impacting our bodies. So, these are important observations that have been made clinically.

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Fantastic. This comes up probably every week on many of the CLL channels that I'm in, and I always roll my eyes, because I just can't believe that this trope still exists.

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So ,let's get it out in the open. Someone keeps reading that sugar feeds cancer cells and I shouldn't eat it.

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Is it true?

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Um, there are not data to say that's true. So, um, the, there are preclinical data looking at sugar and how it affects cellular processing and all of these things. There are also no clinical data in humans to suggest that…

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you're more likely to develop cancer with sugar consumption or that there's any benefit to limiting sugar consumption.

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Now, for the reasons we talked about before. A healthy diet is a good idea, right?

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Um, and we want to, um, the other piece is that, um, you know, sugar consumption leading to obesity puts you at risk for all sorts of stuff, including an increased risk of lymphoma. So, um, there's, you know, indirect links, but…

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as a person with CLL, um, you should certainly partake in your birthday cake, and if you love ice cream,..

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go for it, in moderation, along with everything else.

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No. No, no ice cream while I am in training. Sorry, that's evil. That's just, no. Um, since we're talking about diets, and, um, everybody has an idea about them,..

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are there any, like, really strong do's and don'ts, diet-wise, for folks with CLL?

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So, yes and no. So, there are no data to say that there is a certain diet that is going to help people delay their time to therapy, delay their risk of infection, or minimize the risk of infection, anything like that. So, in the absence of data,..

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I'm of the mindset that people are free to make their own choices. I don't have any strong ground to stand on to say one diet's better than the other.

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Now, for all the reasons we talked about before, if someone is looking to make a change, the Mediterranean diet is probably the one that has the best data basis.

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But, um, overall, not a ton of data to guide us here.

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Okay, so let's, let's take one straight on. Is there anything that us CLL patients should be doing to slow the progression of CLL? Is there any actual protocol that we can put in place to slow this train down?

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Yeah, it's a great question. There are clinical trials looking at that question. So, um, if this is you know, if you are close to diagnosis, have higher risk disease, and this is something that you feel very passionate about exploring,..

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Chatting with your doctor about what trials are available near you to think about, kind of, early intervention is probably the, um, the strategy that makes sense.

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Um, in terms of other things, we are at our center exploring exercise, and hopefully within the next six months to a year, are going to have a study up and running, looking at exercise as a mechanism for reducing infection risk.

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Slowing progression, so um, this is kind of a coming soon, uh, piece, but we do have some data to say that exercise does help, um, with those pieces, so um, that that's a strategy that might make sense.

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Fantastic. Um I'm going to address this one head on, because the question has come up.

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Um, what are your thoughts, good, bad, or indifferent about ivermectin and/or fenbendazole to fight cancer?

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Yeah. Um, there are no data to support the use of ivermectin and fenbendazole in CLL. There have not been any studies to show that it's beneficial, and um, there are some serious side effects that can happen with these therapies, so…

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specifically, risk of liver dysfunction, risk of serious rashes, and then less serious stuff like diarrhea, nausea,..

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rashes, just like, feeling bad that can happen with these medicines as well.

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So if, I typically advise my patients against using these medicines off-label.

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Gotcha. I've got one minute for you. What do you recommend to CLL patients to assist in building up their immune system?

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Yep, so the things that we can do are: the vaccines we talked about, if you have low immunoglobulin levels and frequent infections, thinking about the use of IVIG can be very helpful.

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We do have some data to say that exercise can be helpful, so if people are looking to make changes in their activity level, that's important,..

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um, or that that might be a helpful tool. Those are really the pieces that we can do. And then I talk to people a lot about common sense. So, hand washing, and staying away from people that are sick, and those kinds of things.

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Now, every interaction obviously has its risks and benefits, and when your grandkids are snotty, but it's also Christmas, and you need to spend Christmas with them, like,..

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I get it, you know, there, there are, there's a lot of benefit to that interaction...

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as well as some risk. If you're, you know, next to a stranger who's hacking in a grocery store, maybe just move away from them.

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So.

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Indeed. Dr. Roeker, this has been fantastic, and I want to thank you so much for joining us today. I know that doctors, especially CLL specialists,..

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have an intense schedule, so thank you for fitting us in.

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

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Yeah, no, I want to thank you for your time and, um for all of these great questions, and if there is um, you know, I think there's a lot of talk about CLL specialists, and really excited about working with people who have these specific questions and here as a resource, so.

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Fantastic, that's very well said. We're very grateful for your participation.

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I'd like to thank everyone who joined us today. I know that it's the Friday before a holiday weekend, so participating in this was a big deal, and I'm very grateful.

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I'd also like to thank our generous donors, the CLL Society, and grant support from Genentech for making this event possible.

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A few brief reminders. If you're a Facebook user, please remember to like and subscribe to CLL Society's Facebook page.

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Also, and this is really, really important, please complete the short event survey link in the comment section on Facebook. It'll also be shared with everyone who registered.

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We really need to hear your feedback. We want to know what we did well, what we can do better, and how we can make this event even better. Please join us on July 16th for the CLL Society's webinar Next Generation CLL Treatments:…

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Understanding Clinical Trials, and Future Therapeutic Strategies with Dr. Jennifer Brown.

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Again, my name's Jeff, I am a passionate patient advocate. I believe that all of us can have better outcomes If we take an active role in our own care.

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Thanks for joining all of us today.