CLL SOCIETY

# Webinar Transcript
# CLL 101: Biology, Symptoms, and Diagnosis
### March 26, 2025

*In science and medicine, information is constantly changing and may become out-of-date as new data emerge.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

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

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Hello, and welcome to today's webinar. I am Robyn Brumble, a registered nurse and the CLL Society's Director of Scientific Affairs and Research.

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At CLL Society, we are dedicated to bringing credible and up-to-date information to the CLL and SLL community…

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because we believe smart patients get smart care. As a reminder, you can rewatch all of our educational programs by going to the section of our website called Education on Demand.

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Prior to beginning our webinar today, we would like to mention a few pre-event items.

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

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We ask that you please direct all questions to the Q&A section which is displayed at the bottom of the screen.

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Questions will be sent directly to our moderator, speakers, and CLL staff…

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and are not visible to the audience. After today's event, you will receive a very brief survey that will help us plan for future events.

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We greatly appreciate your feedback. This session will be recorded and made available to everyone on our website.

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Closed captions are available, if you want to turn them on or off, please go to captions and then select “show captions” or “hide captions”.

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This program was made possible through support from both our donors and our industry partners.

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At this time, I would like to introduce our moderator. Thank you.

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Thank you, Robyn. I'm Stephen Feldman. I'm a CLL patient now in my eighth year of remission following frontline treatment.

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I'm a longtime CLL patient advocate, member of the CLL Society's Patient Advisory Board,..

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a senior support group advisor as well as co-facilitator of the City of Hope CLL Society Support Group.

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I would like to welcome everyone to today's event. We are joined by Josie Montegaard,..

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nurse practitioner with the Dana-Farber Cancer Institute in Boston, Massachusetts. Josie will be covering CLL and SLL basics including the biology of the disease,..

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common symptoms, what testing should be conducted, and more. At the end of this event, we will be answering audience questions, so please take advantage of this opportunity and ask your questions in the Q&A box.

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Before Josie's presentation, I want to briefly share some of the resources available from the CLL Society.

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The CLL Society's motto is smart patients get smart care. In this brief presentation, I will show you a few resources which will help you become a smart patient and help equip you to advocate for your best possible care.

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The early part of your CLL journey is the ideal time to begin learning about the disease, finding resources, experts, and support.

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There's no need to take notes. The slides from today's presentation will be available for you to review.

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They will contain all of the hyperlinks to the resources that I will be highlighting.

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The online CLL SLL Patient Education Toolkit is a great way to learn about a broad spectrum of information including the basic biology of CLL and SLL, treatment options, and much more.

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Resources also include preventing infections, recognizing when it's time to start treatment…

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and managing side effects, to name a few. Each topic is presented in patient-friendly terms.

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The CLL Society Medicine Cabinet includes nine of the most commonly prescribed CLL medications in patient-friendly language.

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Each treatment page includes helpful information on dosing, common side effects and how to manage side effects,..

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special considerations, links to financial resources from industry and more. Another great resource that the CLL Society provides is the normal lab values chart and tracker.

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

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In CLL, it's often not one lab report that tells the story, but whether certain levels are trending up or down over time.

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This will inform your questions and decision making. It is more likely that you will be seen by different providers and have blood work performed at different labs.

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The lab tracker becomes an important resource where you can consolidate the history of your lab results in a single document.

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You can bring this tracker with you to medical appointments which is particularly helpful when meeting with a new doctor or just to better inform discussions with your current healthcare providers.

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It is valuable to have predictive cytogenetic testing done at the time of diagnosis.

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Importantly, it is critical, underline critical, to have cytogenetic predictive testing prior to the first and every subsequent treatment.

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The CLL Society’s Test Before Treat campaign; available as a downloadable one-page sheet from our website...

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highlights the three cytogenetic tests that are essential prior to treatment.

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These include FISH, IGVH, and TP53. It is recommended that you bring the test before treat document with you to your medical appointments to help inform this discussion.

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Putting together your team early on in your journey is strongly suggested.

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Have your support system in place. The World Expert is a doctor who lives and breathes CLL.

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Your CLL Expert will direct your overall strategy. They have access to the latest therapies and clinical trials.

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

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

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so your other healthcare team should be in place too. This would include your dermatologist and primary care doctors.

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

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

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Personal support can come in many forms and there are numerous benefits to joining a CLL-specific support group that I will share. Download the CLL Society's helpful list and put your team together.

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If you do not have a CLL expert on your team and you have questions about symptoms, treatment…

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or when to treat, there is the CLL Society's Expert Access Program.

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This program is free and provides a HIPAA-compliant second opinion consultation with a CLL expert physician.

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Afterwards, you will be provided with a written report that you can bring to your local treatment team.

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This program is in place for patients when they have questions about their CLL or their treatment plan and need a second opinion from a CLL expert physician.

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Often the best advice comes from the hard-earned wisdom and emotional balance that can only be offered by fellow CLL patients and care partners who have already experienced the challenges you are facing or the therapy you may consider.

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CLL Society Support Groups are an important resource for education and emotional support.

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For those in watch and wait, there is great benefit for attending support groups with people who have a range of treatment experience for their CLL or SLL.

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Not more than a few members in my own group have expressed that the information and resources they discovered from participating, literally saved their lives.

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In addition to joining a local support group, we have support groups for veterans with CLL, watch and wait, CLL patients without a care partner, and physicians with CLL.

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

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

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The CLL Society will soon be launching the Ambassador Program for one-on-one support around specific treatment options covering targeted oral therapies and CAR T therapy.

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

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The best way to stay informed about breaking research, news, education, and events is through signing up for the CLL Society's This Week email newsletter which goes out every Tuesday.

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You can also find the CLL Society on Facebook, X, and LinkedIn.

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Use this time in the early stage of your journey to get educated about CLL and SLL, and become a self-advocate in your healthcare.

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

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Put together a team and include a CLL expert physician, stay informed with what's new through the weekly email and continue to join us for these important webinars. And without further ado, we welcome Josie Montegaard.

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Hi, everyone. Thank you so much for having me. My name is Josie Montegaard and I'm a nurse practitioner in the CLL department at Dana-Farber Cancer Institute.

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And today I'm going to be talking about CLL 101, Understanding Disease Biology, Diagnosis, and Symptoms.

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So we're going to start really basic. What is CLL? CLL stands for chronic lymphocytic leukemia and it's a slow growing, incurable cancer of the blood.

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It affects B lymphocyte cells, and these cells are normal immune system cells in the body. But when CLL develops, these cells become abnormal and have unregulated growth in the body.

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And over time, they will accumulate more in the blood, the bone marrow, lymph nodes, and spleen.

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At this time, there's no single defined cause of CLL. But we have identified risk factors. These would include age, so CLL often affects people that are older with the median

diagnosis age being in the early 70s, as well as gender. CLL often affects males greater than females.

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We also see some patterns with race and ethnicity. CLL is more common in North America and European countries compared to the Asian countries. And we have identified environmental exposure risk factors, including significant exposure to pesticides such as Roundup and war chemicals such as Agent Orange.

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Additionally, we do know there is a hereditary component to CLL. So if you have a family member that is diagnosed with CLL, you are more at risk of having CLL as well.

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And so, when we think of CLL, it's an interesting disease in that it's considered a leukemia because we can detect the disease in the blood and in the bone marrow, but it also is considered a lymphoma because it's a disease of the lymphocyte cells and can be…

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within the lymph nodes. Within the lymphoma umbrella, there's a lot of different types of lymphomas. So, when we think of CLL, we think of it as a non-Hodgkin's lymphoma.

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And then to further specify, we would consider a B cell lymphoma. And then lastly, we would consider it an indolent lymphoma, meaning that it's a slow growing lymphoma compared to some of the more aggressive lymphomas.

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You may have also heard the term SLL, which stands for small lymphocytic lymphoma.

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And CLL and SLL are often used interchangeably, and this is not incorrect. Biologically, these diseases are the same, meaning that the abnormal cells appear similar on the diagnostic testing.

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But the difference between these two diseases really comes down to where we can detect the disease.

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So, in order to make the diagnosis of CLL, someone must have greater than 5,000 monoclonal B cells found in the blood.

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They may also have enlarged lymph nodes, but they don't have to. In order to make the diagnosis of SLL, however, the person must have enlarged lymph nodes and actually won't have a lot of disease detectable in the blood. They'll have less than 5,000 monoclonal B cells. So again, these are used interchangeably and often the treatments are the same for these diseases. The difference becomes where we can detect the disease.

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So CLL and SLL are often identified incidentally on routine blood work or imaging, meaning that someone isn't coming to their doctor's office reporting symptoms related to the disease. Usually, the diagnosis happens when someone comes in for their annual physical exam blood work and their lymphocyte count is observed to be elevated...

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or maybe someone has routine imaging for a different purpose, such as a woman getting a routine mammogram and an enlarged lymph node is noted on the images. Once there is a concern for CLL or SLL, the diagnosis is confirmed by a flow cytometry test.

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This test can be done on a blood sample, a bone marrow biopsy sample, or a lymph node biopsy sample. And what we will see is the test will show a monoclonal B cell population that tests positive for CD5,..

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CD23 and CD19. It's important to note that in order to make the diagnosis of CLL or SLL, a bone marrow biopsy is not required, nor is full body imaging or additional imaging.

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That being said, your oncologist may recommend some of this testing, particularly if you are nearing treatment, to establish a baseline level of disease.

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So, because most patients are diagnosed incidentally, they usually don't have symptoms at their initial diagnosis of CLL and SLL.

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However, over time, as we continue to not treat the disease and the disease accumulates in the body, that's when people can develop disease related symptoms. These may include swollen, painless, enlarged lymph nodes.

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So, lymph nodes are throughout your whole body, but commonly we can feel them in the neck, under the arms, or in the groin area. And I want to point out that CLL related enlarged lymph nodes are usually painless. So, if you notice some enlarged lymph nodes pop up in your neck or under the arms that are tender to the touch or painful,..

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these are what are likely called reactive lymph nodes. So, your immune system is swelling those lymph nodes up due to some immune trigger in the body. So, we can commonly see these types of reactive lymph nodes swell up in the setting of an upcoming infection or if someone's getting over a recent infection. Also, if someone's recently had a vaccination…

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these lymph nodes will swell up. In reactive lymph nodes, once someone is further away from that immune trigger, the reactive lymph nodes will regress back to normal size.

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CLL-related lymph nodes will swell up, be painless, and often will not regress in size until treatment is initiated.

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Patients also may be noted to have an enlarged spleen. So, the spleen is almost like a big lymph node that hides just under your left lower ribs.

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So, if your spleen is normal sized, you should not be able to feel that. But over time, as CLL accumulates in the spleen, the spleen can become enlarged and create a fullness sensation in that area or sort of a chronic feeling of bloating.

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Also, because when the spleen becomes enlarged, it can take up space where the stomach would normally expand,..

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sometimes people will report early fullness. So, they're hungry, but they can only eat half of their normal plate of food compared to before when they could eat a full plate of food. Additionally, over time as CLL accumulates in the bone marrow, it can cause changes with some of the other blood counts, such as the red cells and the platelets, which are important for blood clotting. And so, as these changes are observed, patients can report fatigue related to anemia…

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or abnormal bleeding or bruising. And then lastly, sometimes people, especially if they're nearing treatment, will report what we call B symptoms. So, this would be unexplained weight loss, drenching night sweats, or unexplained fevers. Again, usually these B symptoms don't occur early in diagnosis, but as someone nears treatment, sometimes those can occur.

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So, after you are diagnosed with CLL or SLL, your oncologist will often perform additional testing to better characterize the behavior of your disease.

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This would include FISH and cytogenetic testing. This assesses for chromosomal abnormalities. And usually this test is helpful once you're diagnosed and then prior to each line of additional new treatment because over time, we can see that patients can acquire new chromosomal abnormalities.

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Additionally, we'll do an IGHV test and patients can either have mutated IGHV, which tends to mean that their CLL will be a little bit more slower growing,..

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compared to unmutated IGHV, where patients will have a little bit more steadily progressive disease. IGHV status does not change through your CLL journey so this test does not need to be repeated at certain intervals through your CLL course.

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And then lastly, we usually will perform some somatic mutation testing, and this is similar to the FISH and cytogenetic testing, and...

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should be done at diagnosis and then prior to each additional line of therapy since you can develop new mutations throughout your CLL journey. So again, the goal of this type of testing is to better characterize the behavior of your disease. Do we predict that your CLL will be more slow growing…

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or a little bit faster paced? And then sometimes, this can help your oncologist identify the best treatment choices for you once you do reach the point of nearing treatment.

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So, when do we treat for CLL? So, we usually follow the International Working Group of CLL criteria for treatment guidelines, and this lists a whole host of different reasons we would treat for CLL.

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I've included here some of the most common reasons I see in my practice.

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But in general, we delay treatment until the CLL or SLL starts causing problems within the body.

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So, this may be due to worsening bone marrow function to too much CLL in the bone marrow. So as CLL accumulates in the bone marrow, the bone marrow is unable to produce some of those normal other healthy blood counts, such as your red cells or your platelets. So, in your regular labs, what this may look like is your white count is sort of ticking up, your absolute lymphocyte count is ticking up. But at some point, we'll actually start seeing your red cel,…

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your hemoglobin, your hematocrit starting to trend down and your platelets start to trend down. A common question patients' often ask me is, what is the threshold that the white count needs to reach before we see some of those other lab changes?

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And unfortunately, that is highly individual to and different for every patient.

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So, if I have someone come in and their white blood cell count is 150 but their red cells and platelets are starting to trend down,..

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they may need treatment at that time. I may then see another patient whose white count is 300, but their red cells and platelets are perfectly normal and stable. So, in that case, I would not treat them. So, it's really highly individualized and…

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while the white count itself can be a nice barometer or a nice marker for you to see sort of what your CLL is doing, really the trigger for treatment within the labs falls on what your red cells and platelets are doing, not what the white count is doing. Additionally, sometimes we will treat when someone develops extremely enlarged lymph nodes or a very large spleen that's causing discomfort or affecting other organs in the body.

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So, if you have really bulky lymph nodes in the neck,..

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sometimes people will report feeling difficulty with swallowing or discomfort with swallowing, that would be a reason we would need to treat.

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Additionally, you can hide a lot of really big lymph nodes in the abdomen. So sometimes if those lymph nodes are pressing on the kidneys, it can cause your kidney labs to start looking a little abnormal. That may be a reason that we would treat. So enlarged lymph nodes certainly would need to be addressed.

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Sometimes we'll treat for a lymphocyte doubling time of less than six months, but this needs to be taken into consideration with the context of what else is going on with the patient.

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So, if your white count is going from six, an absolute lymphocyte count from six to 12, you know that's doubled, but it doesn't necessarily need to be treated. But if your white counts going from 60 to 120 and continues to double in short intervals, sometimes that is a cadence that we would want to address and usually within a short period of time, we'll start seeing some of those other blood…

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counts changing as well. So again, warranting CLL treatment. Another reason we would treat for CLL, is if someone were to develop an autoimmune blood disorder that doesn't respond to steroids or other standard treatment.

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People with CLL are more at risk for autoimmune disorders in general, due to the immune dysfunction that the CLL causes. And often, we will see people develop autoimmune anemia or autoimmune low platelet counts. And usually this is manageable by just a steroid course. However, if someone has a steroid course and they do not respond to that, or if they respond but shortly thereafter have another flare in the disorder,..

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then sometimes we'll jump to treating the CLL itself as we feel like this is the underlying driver of the autoimmune process.

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And then lastly, sometimes we will treat for significant CLL related symptoms such as those B symptoms, unexplained weight loss,..

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drenching night sweats or unexplained fevers. But I will say that usually when these are happening and it's very clearly related to the CLL, someone else is meeting the criteria for these other reasons to treat. If you have a really low volume of CLL, and you're having significant B symptoms, other diseases and…

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processes in the body health conditions can cause these B symptoms so it would be important to work that up for other causes and not just blame the CLL, especially if your overall disease burden is still quite low.

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So until you meet the criteria for treatment and start CLL treatment, we would consider you as taking part in active surveillance, meaning that you usually will see an oncologist every three to 12 months and at those visits have blood work, physical exam, and a health history update so that we can keep an eye on the CLL and know when is appropriate to start treatment.

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You may be asking yourself, why don't we treat CLL at the get-go? There are a few reasons for this. One being that because CLL is such a slow growing disease, some people, depending on when they're diagnosed, may never actually need treatment.

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So why introduce treatment from up front and introduce side effects or potentially other health complications because of the treatment when they may not need treatment overall in their lifetime anyway?

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Additionally, there have been a variety of different studies that show that there's never been an overall survival benefit for early intervention with chemotherapy or newer targeted therapies. And this would include for patients even with some of those more aggressive disease features. And these studies also show that really the difference between…

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the early treated people and the delayed treated people, the only real difference was the side effects. So, people that were treated early, understandably, reported more side effects than people that had delayed treatment.

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And then lastly, while we do have excellent treatment options for CLL, these are not infinite in number. So, we really prefer to delay treatment as long as possible to preserve all of our great treatment options for down the road should they need them. Also, this allows the research to sort of take its course so that more treatments are…

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discovered and FDA approved that you can use in the future.

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Now, because of this sort of delayed treatment model, we understand that this can take a significant emotional toll on the patient and the family. It's not every day that you come across a cancer that you have been made aware of but told we're not going to treat you until you start feeling badly from it.

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And so, it's not uncommon that I see many patients walk through my door saying they feel like there's this black cloud hanging over their head or they're constantly anxious waiting for the next shoe to drop. And so, if you're feeling this way, it's really important to communicate that with your oncology teams. Oncology centers often have great resources to help with your emotional health, whether that be social work, psychology, or complementary therapies such as Reiki or acupuncture. So, it'd be important to tell your oncology…

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team that you're struggling, because they can help connect you with those resources.

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I've also found that it's helpful to stay up-to-date about your diagnosis and what's going on in the field. Doing a program like today is exactly what can be helpful to just understand what's going on with you right now and what the future may look like.

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And then lastly, utilize support groups and involve family and friends as you feel comfortable. This is a journey that no one should have to walk alone in, and find out, think about what would be a great support for you, and engage that person or those people.

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Additional actions to take during the active surveillance phase is to make sure you stay up to date with your routine cancer screenings. So, we do know that CLL and SLL patients are more at risk for secondary cancers and in particular, those are the low-grade skin cancers such as your basal cell carcinomas and squamous cell carcinomas.

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So, it's important to not lapse in any of the routine cancer screenings we have available so that would include your colonoscopies, your mammograms, pap smears, PSA testing, at least an annual exam by a dermatologist. And then I also include here bone density testing as patients with CLL are more at risk for osteoporosis.

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And then, we also would want you to stay up to date with your seasonal and routine vaccinations.

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Even untreated patients with CLL and SLL are considered immunocompromised and more at risk for serious illness from infections.

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So, I list here some of the routine vaccinations that you should make sure you're staying up to date with.

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With the caveat that you should not be receiving any live virus vaccines. So a real hot topic right now in the world, is the outbreak of measles in various parts of the United States. So unfortunately, the measles virus vaccine, MMR, is a live virus vaccine. So, if you've not gotten that in the past…

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or feel like you don't have antibodies anymore against measles, unfortunately, this is a vaccine that we would not recommend you repeat even despite the outbreak.

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Some other common live virus vaccines are some of the travel vaccines so if you are planning to travel to an area that requires travel vaccines, certainly consult your oncologist about which ones you can have.

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And then lastly, we want you to stay active. There are so many studies showing how important physical activity is in promoting a good energy level, combating fatigue, and then also helping your overall health, including cardiovascular health and whatnot, which can be helpful should you need CLL treatment in the future…

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to make sure that there's every treatment available for you and you don't have a condition that would prevent you from receiving a certain treatment that would be good for you.

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So, in conclusion, CLL is a slow-growing cancer of the blood and at the present time is considered incurable.

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At diagnosis, we would recommend that you have molecular and genetic testing in order to help predict the behavior of your disease and this can also impact treatment decisions for down the road.

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Treatment itself is deferred until patients become symptomatic from their CLL. And after diagnosis, patients should prioritize both physical and mental health.

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But you know, the future is really bright for CLL. We've really come through a renaissance in the disease where even within the last 10 years, five new therapies were FDA approved, which is unheard of in the oncology space.

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Additionally, with more treatment options available, we are better able to tailor CLL treatment to the individual patient. So, it's quite rare that you will need treatment and your oncologist is going to say, “this is the treatment we have available, take it or leave it. Often, we're giving patients a menu of options so that we can really…

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discuss what would be best for the patient, what's meaningful to them, and choose the most appropriate treatment choice.

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Additionally, with the treatments we have available, patients are achieving deeper and longer lasting remissions despite shorter treatment durations.

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So while we still have some continuous indefinite treatments that we recommend for patients, many of our other treatment choices are one or two year treatments that then will be stopped and patients will be in a remission and have time off treatment. So, treatment breaks can be really helpful. And then lastly, there are so many active clinical trials exploring promising treatments for patients with more aggressive…

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disease biology and resistant disease. So, if you fall into that category, a lot is coming down the pipeline that should help you in the future.

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And with that, thank you so much for having me. And I'd be happy to answer any questions.

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Thank you, Josie. That was a fantastic presentation. You covered a lot of territory. And just a reminder for people that this webinar will be posted and available On Demand.

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I remember back years and years ago when I was considering what my treatment options are, I would find several videos available at that time, that's going back eight years or so ago.,.

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eight years or so ago now, and I would watch them over and over again until I absorbed all of the concepts and all the vocabulary.

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So, let's get to the audience questions and we've got lots of them. We'll try to get to as many of them as possible, but with the time allotted, we certainly won't get to all of them…

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so apologies for that. If we don't get to one of your questions, please remember that you can email our Ask the Expert and that email address will appear at the end of our a presentation on a closing slide. So, let's get to some of the questions.

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Are you ready, Josie? Okay. When is FISH testing recommended?

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Yeah, I'm ready.

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Yeah, so as I mentioned in the presentation, the first time you should be having FISH testing is at diagnosis or at the very least, before you start your first line of treatment. This can be predictive in terms of what the behavior of your CLL will be...

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but also can be impactful in the treatment decision-making process. So, that would be the first time you should have it done.

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As in the presentation I mentioned, over time, we can see new mutations in chromosomal abnormalities be acquired in certain patients that have received different lines of therapy.

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So, if you are about to go on to a new line of therapy or are progressing on your current line of therapy, it would be important to repeat that testing to sort of reassess your CLL and get to know it all over again.

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Great, thank you. Someone writes, has there been any advancement in early treatment options specifically for people in stages zero to one?

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And I thought maybe it might be helpful if you could describe the different staging protocols for CLL.

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Yeah, so stage zero to one CLL usually means that someone is pretty asymptomatic from their disease so they're absolute lymphocyte count may be the only thing that's elevated and cueing anyone to know that they have CLL...

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or they may have just an isolated, slightly enlarged lymph node, but they certainly usually won't have any CLL related symptoms...

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nor will they have any changes in their other blood counts, such as their red cells or platelets…

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that would warrant intervention. You know, there's still a lot of active research going on into looking at different types of treatment…

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to be initiated prior to when we would normally consider CLL treatment as per the iwCLL criteria for treatment. But that being said, so far, the standard remains to delay treatment until someone is truly symptomatic from their disease.

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Again, because a lot of our treatments may just introduce new side effects or potentially make you even more immunocompromised…

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and do not impact overall survival. So more to come on that. It takes a really long time to get overall survival data so some of the active trials that we have now may change that thinking. But for now,..

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we still would delay treatment until it's absolutely necessary.

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Thank you. The next question concerns immunoglobulin testing, which isn't always done at every visit,..

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and many people might not know that there are different types of immunoglobulins - we have IgG,..

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IgA and IgM. So one person writes, for patients receiving monthly IVIG treatments,..

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is it concerning for the IgG to be normal while the other IgGs or the other IgGs like IgA and IgM continue to drop…

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and might this be related to treatment from Gazyva or obinutuzumab?

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Yeah, so any CLL treatment can impact your immunoglobulin levels. And IVIG can be really helpful in replenishing the IgG level…

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but it usually does not impact your IgA level or your IgM level, so it's not concerning that those are not uptrending...

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from your IVIG infusions. And unfortunately, there's no other repletion method to supplement your IgA or your IgM and actually in some cases,..

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people with CLL can actually have extremely elevated levels of IgA or IgM. So everyone is a little different, but as long as your IgG is improving with the IVIG infusions,..

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that's really the goal of that.

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Great, thank you. Next writer. Other than receiving, quote, customary lab testing every four months like a CBC, what other types of blood work are recommended? Should I be asking for more extensive blood tests?

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I don't think any more extensive blood tests are needed as long as there's no concern about a change in your CLL status. So, when our patients are coming in for their routine blood work, we're including CBC, a comprehensive metabolic panel that would look at your organ…

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function testing such as your kidney tests and liver tests, as well as your electrolytes. And we will also do an LDH, which is a nonspecific marker for inflammation in the body.

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Sometimes it can be tied to CLL activity, but it also can be tied to generalized inflammation and even other types of lymphomas so we sort of keep an eye on that as well. But outside of those basic lab tests, we don't often…

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do repetitive immunoglobulin testing or some of the more diagnostic testing such as the cytogenetic and FISH testing, unless there's been sort of a change in the disease course.

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Thanks. Let's say you get to the end of your treatment and you're MRD negative.

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Does that mean you're now immune? Are you still immunocompromised or not?

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So it really depends on what the type of treatment is that you received.

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Across the board, I would say that any CLL patient, regardless of where they are in their treatment course -..

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untreated, in the middle of treatment or post-treatment - is to some degree considered immunocompromised.

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That being said, once you are in a complete remission and you're multiple months out from treatment, your immune system should be regaining some functionality.

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There are some tests that we can use to help gauge your immune system function. The immunoglobulins, your IgG level can be one of those.

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Monitoring your absolute neutrophil count can be another way we monitor your immune system. So those are your good infection fighting cells. And then if you're someone that has received chemo immunotherapy for your CLL in the past, checking a CD4 T cell count can also be helpful to monitor immune system functionality. But it really depends on the type of treatment you've had…

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and some of those testable markers.

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Thank you. I know you've addressed some of this already, but someone writes, what tests should be performed during active monitoring?

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Yeah, so during active monitoring I would definitely do those blood counts we just mentioned, the CBC, the metabolic panel, the LDH.

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We also will do occasional immunoglobulin testing. You know, if someone's reporting a lot of infections or recently had a significant infection,..

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we'll test the IgG level. If it is low and they are having infectious complications, then repleting it with the IVIG infusions could be helpful in boosting up their immunity.

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But outside of that, there's no other routine testing that I'd recommend, again, unless there is a change or concern for a change in the disease status.

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Great. Someone writes that they are 97 years old and they were recently diagnosed with CLL.

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Is there an age at which you might be too old to start treatment?

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No, age is just a number. So I think, you know, it all depends on the person...

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and the timing at which treatment's needed, what other health conditions are of concern. But if someone truly needs treatment for CLL and there's no other health problem that would make us concerned about giving a certain CLL treatment, we will treat people at any age. I certainly have a fair amount of 90 plus year olds getting some form of treatment and doing really well.

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Thank you. Someone writes, they're interested to know if there's any research data showing a connection or a correlation between CLL and other medical conditions, neurological or cardiological, etc.?

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So fortunately, with CLL, we don't often see CLL involvement of the central nervous system so this is not one of the types of cancers or diseases that we often see neurologic complications from. I think I've only seen a handful of those cases in my career.

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And as far as the other organ system goes, CLL very rarely can have what we call extra nodal involvement, meaning that we can find little pockets of CLL cells in other organs that then may cause patient symptoms or problems with those organ functions. And sometimes that may be a reason, an atypical reason, that we would treat their CLL.

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For instance, we can see commonly CLL populations and tonsils so if someone's having repetitively enlarged tonsils or tonsillitis and then the tonsils are biopsied and a CLL population is found there sometimes we would treat for that reason. So that's where CLL can often impact other organ functions but again, that's still quite rare but a instance that I could see that happening.

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Thank you. The next question is a little bit patient specific.

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The person writes that they are experiencing muscle and joint pain while on venetoclax…

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and wondered whether some of the cholesterol treatments like cholesterol Provocal or Zetia might be suitable for treating any sort of muscle or joint pain?

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So if you need treatment for your elevated cholesterol, cholesterol, statins such as pravastatin, atorvastatin and the like can actually cause myalgia, so some muscle aches. So, it may not be the best option if you're already dealing with joint aches on top of that. We wouldn't want you to become physically limited because of a variety of aches and pains.

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So that would be important to discuss with your cardiologist and see if there is other suitable alternatives.

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But if there are not any other suitable alternatives for managing your cholesterol, then I think it's certainly worth trying to go on both at the same time.

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You know, with regards to the arthralgias or muscle or joint aches that we can see from venetoclax, we can also see those with our BTK inhibitor drug class as well. The first thing I would do is confirm that the aches truly are related to that medication.

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Many people have pre-existing arthritis that sometimes can flare on these treatments or sometimes may be totally unrelated to the treatments themselves. And we would hate to dose reduce or stop a medication early without knowing that the aches are directly caused by the medication. So, someone comes into my office reporting joint aches that we think may be related to their CLL medication,..

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we may try a brief drug hold to see if the aches go away.

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If they don't, then I would venture to say the aches may be due to something else and I'd recommend resuming at full dose. But if they do very quickly go away, then it can become a conversation between yourself and your oncology team about whether a

dose reduction may be a happy medium to preserve your quality of life and keep your CLL under control.

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Thank you. The next question comes up very frequently, and it's the effect of diet on CLL. Are there any foods that should be included or avoided? And then a related question,...

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outside of improving one's general health, are there any specific lifestyle changes that could be helpful? And I realize this could be its own webinar or series of webinars...

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but give it your best shot.

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Yeah, so it definitely opens Pandora's box. But I think in general, there's no specific dietary modifications we recommend making in order to better your CLL. We recommend just a balanced healthy diet, really to promote your overall health in all respects to reduce your risk of cardiovascular disease,..

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diabetes and other health complications. As I said in the presentation, sometimes if your other organs are not functioning optimally because of poor diet or not enough exercise or whatnot but when you need your CLL treatment, we may say we would normally give you this treatment, but…

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we're worried about your heart or we're worried about your kidney function or whatnot. So really making sure all your other organs and whole body is functioning as healthily as possible is going to benefit you down the road.

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And that same, that goes similarly from diet as well as lifestyle interventions. So getting out and exercising every day, even if that means a couple laps around the house or a walk to the mailbox and back, that's better than nothing.

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Staying up-to-date or on top of your mental health as well, because I think a sedentary lifestyle and having untreated anxiety and depression can go hand-in-hand and this is a very challenging diagnosis and sometimes you don't realize that your mental health may be affecting your physical health as well.

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I'm reminded that grapefruit is contraindicated when you're on certain medications,..

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can you elaborate on that?

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Yeah, so when you are on a lot of our oral CLL medications, so our BTK inhibitors and venetoclax, which is a BCL-2 inhibitor,..

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these can interact with certain fruits. So, grapefruit is one of them, starfruit is one of them  and Seville oranges, which are bitter oranges that are not oranges you see typically in the grocery store like your navel oranges or mandarins,..

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they are what we typically make orange marmalade out of. So, if you are on any of those oral therapies…

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I would recommend stopping eating grapefruit, starfruit, and Seville oranges. And as well, there are quite a few supplements that sometimes can interact with CLL treatment. So, it's really important to be transparent with your oncology team about what you're taking, both prescribed medications as well as over-the-counter and supplement medications so that we can check to make sure there aren't any…

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interactions.

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Thank you. Someone writes, is CLL hereditary and are there tests to screen if a family member might develop CLL in the future?

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So we do know that there is a hereditary component to CLL, so if you do have a family member who has CLL, you may be more at risk for CLL. That being said, there's no recommended screening for family members or tests from family members to see if they have CLL.

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And that sort of goes along with the thought that we don't treat CLL at diagnosis. So, there's not often a benefit to knowing you have CLL sooner rather than later. And often

that can have an emotional toll on a family member if they were to know right from the get-go that they had CLL as opposed to maybe not finding out for a few years when…

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for other reasons or their labs change that would warrant work up for CLL. So, it's important to be aware of, to let your family members know of the slightly increased risk, but we wouldn't recommend any additional testing to diagnose them as early as possible.

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Thank you. Someone writes, in what instances should a second opinion be sought from a CLL specialist?

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So, I think that it's helpful to see a CLL specialist if you are nearing treatment or if you are considering a change in your treatment choice.

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These situations, a CLL specialist can help repeat all of those prognostic tests to again, make sure we truly understand all facets of your individual CLL. And sometimes CLL centers have access to these tests a little bit more readily than community sites.

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But also CLL centers have access to many clinical trials. They could offer you maybe more treatment options than your local oncology office or they may say, do exactly what your local oncologist is doing. And then you know that you've heard it from someone who does this every day.

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The other common reason that I'd recommend seeing a CLL specialist before starting treatment is because there are quite often people coming to us for initial consultation being told that they need CLL treatment. But when we look at their labs or look at…

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their scans or whatever they've had done, we realize that they actually don't need treatment and we may save them starting treatment for a year or a couple years. So, it would be helpful to confirm with a CLL specialist that treatment is truly indicated at the time that your local oncologist is recommending it.

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I think it would be helpful just to uhm, elaborate more on exactly what is a CLL specialist? I mean, is your local oncologist, they have a subspecialty in oncology, are they a CLL specialist?

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Yeah, so I would consider a CLL specialist someone that primarily focuses on CLL. So, at our institute, we have three doctors who focus heavily on CLL. Those are pretty much the only types of patients that they see, even within our lymphoma department.

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But if you have a center that has a dedicated lymphoma department and an oncologist is listed as having a CLL interest, I think that also could qualify as a CLL specialist.

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Someone, an oncologist that does not specifically see lymphoma and CLL, I would not consider a specialist. So, if they're seeing every type of blood cancer or every type of cancer in general, both blood and solid tumor cancers, that would not be a CLL specialist.

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Thank you. The next question concerns Roundup. I think, perhaps many people who are Googling CLL may find that their social media algorithms are bringing up feeds, ads from people from law firms who are representing people in class action suits…

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to recover funds from Roundup. How do you know if your CLL was caused from Roundup? Maybe you first want to tell us what Roundup is and then once you have CLL, can a pesticide like Roundup impact the progression of it, of your disease?

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Yeah, so, so Roundup is a pesticide that is commonly used to treat lawns and other plants.

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We tend to think that for the people that whose CLL was caused by Roundup, they had pretty heavy exposure. So, if you were maybe a groundskeeper at a country club and were spraying Roundup day in and day out, you know that may be a…

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good contributor as to why you have CLL today. But if you used it sort of occasionally in your yard to treat weeds sparingly,..

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I'm not sure that that would necessarily be the primary driver of your CLL. We don't really have any tests to firmly link a specific cause of people's CLL so this is all sort of hearing someone's story and someone making a best guess, educated guess.

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So, it's sort of hard to link directly. But I would say if you had significant exposure, a lot of occupational exposure, that may contribute. But if you used it just sort of sparingly around your yard,..

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less likely. And then as far as whether that impacts the type of CLL you have, I don't believe we are aware of any links between a certain, certain type of CLL and prior Roundup exposure.

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Thank you. The next question concerns our white blood cell counts and the numbers.

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So, I think there's a lot of confusion about whether there is a certain threshold in the white blood cell count that would trigger treatment.

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Yeah, so usually there's not. And I think that's a really unsatisfying answer for many patients because, you know, you're trying to have a best guess as to when treatment may be initiated and sort of prepare yourself.

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Unfortunately, the white count itself really is not a trigger to initiate treatment.

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Really, it's what your other blood counts are doing and what symptoms you have associated with your CLL that may warrant treatment. So, I think I gave the example in the presentation where I may see one patient in my clinic and their total white count is 150 and we're starting to see that their red cells are going down and their platelets are going down. So that tells us that..

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even at that level of CLL, at the white count of 150, their bone marrow is suffering. There's too much CLL in their bone marrow. And so, the bone marrow is not able to produce those normal other cell lines.

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So, in that case, we may initiate treatment at that white count.

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But then I may see another patient whose white count is 300 and for whatever reason...

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their bone marrow is still working great. Their red cells are normal and stable. Their platelets are normal and stable. So, in that case, we continue to observe them even though their white blood cell count is double what that first patient's was. So, it really is highly individual. That's where trending the white count can be helpful just to sort of…

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assess the cadence and the speed at which the white count is rising or not. And then, also focusing a lot on what those other blood counts are doing. I think they get underappreciated when people are making their graphs and things of how their blood counts look, really pay close attention to what the red cells and platelets are doing too.

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I'm going to follow-up with that and ask you to describe when it's necessary to have a bone marrow biopsy…

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because you can obviously have a very high white blood cell count from a peripheral blood draw, but what would suggest that you need to dig deeper, dive deeper and have a bone marrow biopsy?

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Yeah, so sometimes we'll do a bone marrow biopsy prior to initiating treatment if something uhm, seems awry or atypical of the CLL.

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I can think of if someone's starting to have low red cells and low platelets or even low good white cells, the neutrophils,..

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that seems more dramatic than what it should be based on what the circulating white blood cell count is or how the person is feeling. If we're worried that maybe there's a lot of disease in the bone marrow that's not being observed in the blood, we can do the bone marrow biopsy to understand if CLL treatment is needed then.

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Also, the bone marrow biopsy can be really helpful in differentiating what is an autoimmune blood disorder, such as autoimmune anemia,..

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versus the CLL, overcrowding the bone marrow and that causing anemia. So, there's a lot of different reasons we would do the bone marrow. Also, sometimes we'll do it just to

confirm that there is a lot of disease in the bone marrow before we initiate treatment. Usually when we see…

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the red cells and the platelets go down because CLL is overcrowding the bone marrow, someone has about 80 to 90% involvement in their bone marrow.

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So bottom line, there's a lot of reasons, but I think atypical lab values that aren't consistent with the overall CLL burden would be a reason. And then if we really want to confirm whether the CLL is driving those other low blood counts, that could be a helpful use of a bone marrow biopsy.

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Thank you for that explanation. Getting back to diet, sort of, somebody writes,..

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do carbohydrates, probably meaning sugar, feed CLL? Because there's a lot of conversation out in the interwebs that sugar feeds cancer. I think that's been disproven, but I don't know for a fact. Can you elaborate on that?

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Yeah, so carbohydrates feed all of the cells in your body. So, you know, you're CLL cells are going to use up any of the nutrients that you're getting from any type of food that you're taking in along with your other regular cells. So that's…

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for that reason, we don't recommend low carbohydrate diets or any other diet modification because those nutrients are not just going to the CLL cells, they're going to everywhere else too. So, it's important to fuel your body just as you normally would.

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Great. What is the difference between remission and MRD, minimal residual disease?

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Yeah, so to achieve a complete remission, someone must have undetectable CLL in the bone marrow by flow cytometry testing…

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and have no enlarged lymph nodes by CT scan. And when we think of MRD, which stands for minimal residual disease,..

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this is a more sensitive test than even flow cytometry testing to look for microscopic levels of CLL that may remain in the blood and in the bone marrow.

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This type of testing is quite new. And because of that, it's not listed as a criteria that someone needs to have in order to achieve a complete remission. So, someone could have a complete remission but still have some detectable microscopic disease…

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so therefore, be MRD positive. You know, we're still heavily exploring the use of MRD and how that should guide, you know, treatment durations and counseling patients on the duration of remission that they should anticipate based on their other CLL features. But the big differentiating factor between remission and MRD is that you can have…

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detectable MRD, but still be in a complete remission because it's the remission test is not quite as sensitive.

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What is the distinction between minimal residual disease and measurable residual disease?

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So minimal residual disease, depending on the type of assay that you're using,..

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can detect one CLL cell in sometimes even in a million cells. That is a test that is called ClonoSEQ.

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Whereas measurable disease is what we would look at by our regular lab work, our flow cytometry testing and our CT scan. So, flow cytometry tests often can detect CLL cells as sensitive as one in 10,000 cells. So, there's a big difference between detecting disease…

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and on a scale of one in a million versus one in 10,000.

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Thank you. Here's a question, may be confusing some people.

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Please comment on whether or not CLL SLL patients on oral immunotherapy should avoid yogurts containing live active cultures.

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So, the only time that I would caution my patients against having yogurt with live cultures is if they have a problem with their good infection fighting cells, the neutrophils. The reason being is sometimes if you are taking in too many of those…

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good live cultures into the gut, if you don't have good immune defenses, such as a good neutrophil count to keep that bacteria contained in the gut, that bacteria can migrate elsewhere and cause other infections in the body.

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It's not typical that someone on oral CLL treatment would have prolonged periods of low neutrophil counts or prolonged periods of being severely immunocompromised. So, for the most part, I don't caution people against having the live culture yogurt or doing like a probiotic, for instance.

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But if you do have some of those, those lab abnormalities, then it may be helpful to avoid it.

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Thank you. What is the role of CAR T treatment? First maybe you can describe what it is and why is it, you know, typically not offered as a frontline treatment rather than for people who are relapsed or refractory.

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Yeah, so CAR T cells are, uhm, is a therapy that's very widely used in other types of lymphoma and other types of blood cancers and is actually being explored in solid tumor cancers, as well. Basically what happens, is we take your own T cells out of your body. We can do that by inserting a catheter into your vein and…

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taking out the cells we want and putting the rest of your blood back into your body as an outpatient procedure. And we send those T cells over to a lab where they're then manufactured to identify certain targets on the CLL cells or the other types of cancerous cells. And then once that's manufactured, they're given back to you, usually in the hospital and…

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those cells help your immune system target the CLL cells and get rid of them.

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Now, CAR T cells can come with a variety of different side effects that can be life-threatening potentially. So that's why it's not typically given in the upfront setting because there are some, some significant risks associated with it. These may include neurologic side effects or seizures, as well as a phenomenon that we call cytokine release syndrome, which can result in…

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drops in your blood pressure and high fevers. Again, these are sort of all why these side effects are the reasons we give this type of treatment, usually in the hospital, so we can monitor you very closely.

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But because we have safer and really effective oral therapies or less invasive therapies for CLL, we tend to prefer those first,..

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preserving things like CAR T cells for a later line of treatment.

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Also, the data for CAR T cells is mixed. Some people have had an excellent response to CAR T cells in the clinical trials that got them approved for CLL, but others did not. And there's still a lot of research focused on why did some people do well? What about their CLL or their treatment course got them to do well? And how can we…

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use that information to make it so that the CAR T cells are more broadly effective for a lot of CLL patients and not just for a small subset? So there's still a lot of research into figuring out how to best use them in the CLL space. But in the meantime,..

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we do have a lot of other very effective oral agents or combination treatments that would give people a nice remission while we sort of sort out how to optimally use the CAR T cells.

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Here's another treatment-related question. Someone writes, can CLL be cured via cell transplant?

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I think they were probably referring to a bone marrow transplant. So, is that done anymore?

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And who would be the candidate for that?

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Yeah, so CLL theoretically can be cured from an allogeneic stem cell transplant. So that's when someone receives donor stem cells, not stem cells that were collected from their own bone marrow, but stem cells that they received from a family member or an unrelated donor.

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We don't often do allogeneic stem cell transplants for CLL patients because there is still a risk that you can relapse after the transplant. And transplants come with a heavy amount of side effects. You know, you can have graft versus host syndrome, which is when your body sort of rejects some of those donor cells...

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and you also can be severely immunocompromised for quite a while. So CLL patients are already at risk for infection and then you add another layer of suppressing your immune system on top of that,..

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that can result in a lot of infectious complications after the transplant is done. So for that reason, and again, because we do have such good less invasive other types of therapy, we tend to not see the allogeneic stem cell transplant used commonly anymore.

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I'm going to ask a maybe related question for people who've been on immunotherapy like Gazyva or obinutuzumab.

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Which wipes out your B cells? Does it wipe out only the CLL cells or all of your B cells?

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And I know it affects your ability to respond to vaccines.

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How long do you have to wait after being treated with one of these immunotherapies before you can get vaccinated and have a response?

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Yes, so it can wipe out other types of B cells. And so for that reason, we do see that people can have an inability to respond to vaccinations while they are getting medications such as obinituzumab.

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We say that the effect should last about six months after you finish your last dose of obinutuzumab. So, if you finish your last dose in June, you're likely not going to have a robust response to vaccination until at least December.

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That being said, everyone is a little different. So, you know, when we were heavily testing people's COVID antibody titers post-vaccination, you know, when COVID initially arose,..

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we would find that sometimes even people that were over six months out from their obinutuzumab still, we're having diminished responses to the COVID vaccines. So, the six months is sort of looked at as a minimum,...

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a minimum amount of time that it would take your B cell population to become more functional again, but sometimes it can be much longer.

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Thank you. Now, you bring up COVID, and interestingly none of the advanced questions that we received ask about COVID. So, what is that looking like these days?

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Yeah, so, you know, this year actually wasn't too bad of a year for COVID. I think flu A sort of took over as the dominant infection that we saw through the primary cold and flu months, the post-holiday months.

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But COVID is still something that we need to be aware of and be careful about when it comes to identifying exposure risks and managing that as we're able to. I would say patients that have not received CLL treatment or are extremely far out from treatment, multiple years past their last line of therapy,..

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probably would fare the best in terms of their response to COVID vaccines and their response to getting actual COVID infection.

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But for people that are newly post-treatment or having active treatment, we can see still significant COVID infections and prolonged COVID infections, which I think can actually be even more bothersome and problematic for patients. We have patients that get a COVID infection and are testing positive…

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for weeks, if not months thereafter, because their immune system is not able to clear the infection. And the longer that you have an active viral infection, the more at risk you may become to developing bacterial pneumonia…

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or other respiratory complications. So, things that we recommend to help with COVID is obviously staying up-to-date with all of your COVID boosters and vaccines,..

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also being transparent with your oncology team if you do test positive for COVID, we primarily recommend Paxlovid as the first treatment choice for COVID, but if that's not available,..

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or it's not appropriate for you, then remdesivir or another type of antiviral may be recommended.

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And if you are on active CLL treatment, I'm thinking of some of the oral treatments are venetoclax or our BTK inhibitors,..

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often we will have patients hold those while they are on their COVID treatment and even after until they are starting to test negative, because sometimes that can impair clearance of the virus.

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Thank you. Somewhat related, someone writes, I've had pneumonia twice since being diagnosed with CLL in 2022.

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Is this due to my compromised immune system?

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Yes, it likely is. If you've had multiple infections and you've not had your immunoglobulins, for instance, checked recently, I would recommend discussing that

with your oncologist because that could be contributing and that's something that we can do something about. We could start infusions of…

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IgG which may help boost your immune system a little bit better. But outside of that, just being aware of exposures to different illnesses, especially around the holiday months and winter months...

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and avoiding exposure if possible will help you sort of not get pneumonia but and then as well, sometimes our patients require longer courses of antibiotics. So that's, as well, something that you could discuss with your care team if you feel like you're…

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having an incomplete response to the standard courses of antibiotics. Sometimes our patients need longer courses.

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Thank you. The next question sort of goes to where did I get my CLL? How did I get it? The person writes specifically...

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that they had been a bone marrow donor, 25 plus years later, they were diagnosed with CLL. Is there any connection between the two?

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I don't believe there would be a connection between having given prior bone marrow donor sample and now having CLL. You know, we really don't know of a single defined cause. Sometimes someone has none of the risk factors that we've been able to identify and still get CLL. So that's where a lot of, some of the laboratory research is headed.

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We have a big CLL biobank where we collect samples of blood and other tissue from our patients that consent to it. And that allows us to study different samples from different types of people and better understand, you know, are there connections between..

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their CLL and their prior health history or other factors in their lives. So, a lot more to come on that subject.

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I think that many people are under the assumption that when they get their CLL diagnosis, it means that the disease presented itself may be a year or two prior to their discovery of it.

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My understanding, though, and I might be mistaken, is that the CLL could have started many years prior to its discovery given how slow growing it is.

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Can you elaborate on that?

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Yeah, so that's definitely correct. Many people probably have had CLL, at least some trace of CLL, for years and years prior to their diagnosis. We know of a precursor condition called monoclonal B-cell lymphocytosis and so this is a condition where someone has…

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those abnormal B cells found on flow cytometry, they don't have any enlarged lymph nodes and they have less than 5,000 cells found in the blood.

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So, when people get diagnosed with this condition, which stands for, uh, we term it MBL, they may develop CLL over time or they may not.

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But many people that have CLL, at one point or another, probably started as having MBL and that was left undetected and eventually those abnormal cells accumulated enough to meet the diagnosis of CLL and that's when someone had the flow cytometry testing.

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That being said, you know, CLL behavior is really heterogenic.

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There are some patients that have aggressive disease features. So in that case,..

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when they get diagnosed, sometimes I will tell them that I don't think you had this long before we started seeing abnormalities and your blood counts or in your lymph nodes that warranted the testing that led to the diagnosis. So, in those select instances, I would say maybe someone only had it for a year or two, but for most people...

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it's likely those abnormal cells were hanging around for much, much longer.

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Thank you. This is probably the last question. Someone writes, it is suggested flow cytometry testing should be accomplished at certain events.

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However, my husband only had this test once in the beginning of his treatment three years ago…

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by a different hospital and medical staff. Should, and when should, he get another updated flow cytometry?

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So, flow cytometry is done to diagnose CLL and then often it's done as someone is nearing treatment, especially if they are having a bone marrow biopsy or other types of restaging assessments prior to initiating CLL treatment.

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Though you don't necessarily need to have it then, it just often is performed as part of the global assessment of where the disease is prior to initiating treatment to establish a baseline.

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But outside of that flow cytometry, testing in some form may be done to evaluate the treatment efficacy.

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So, if you're having, if you're on say venetoclax, for instance, and are nearing the end of your one or two years of treatment…

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sometimes flow cytometry testing will be done in lieu of minimal residual disease testing to look for any lingering CLL.

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Often now, we are doing more of the more sensitive testing in that case, but the flow cytometry could give you a good idea of whether you had any circulating disease left. And then lastly, sometimes we'll do flow cytometry testing if we're worried that another disease process may be at play. So if your CLL is…

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looking well under control and some new problems in your blood counts or how you feel arise and your oncology team is concerned that something else is going on, sometimes we'll do flow cytometry in the bone marrow or in the blood to further evaluate that…

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but the other prognostic testing is a little bit more important to do at certain intervals in your disease course.

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Thank you, Josie. Well, that brings our Q&A section to a close.

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I'm going to ask Josie if she has any closing thoughts for us.

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And I might suggest, because I know that these webinars present just a volume of information and it can be overwhelming.

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So maybe a closing thought might address how do you absorb all of this information?

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Yeah, so I think that it's a lot of information all up front and so finding ways to, uhm, to hear the information in smaller snippets is really helpful. So, presentations like this are recorded, o being able to play back…

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different sections can be helpful so you can sort of digest one piece at a time.

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Additionally, when you're going to your oncology visits, having another, another set of ears there can be really helpful because you may feel sort of overwhelmed with them out of information and miss, you know, pieces of it, but your second set of ears, your caregiver or…

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family or friend, whoever's with you, may be able to take notes or catch some of the information that would have gotten lost on you. And that's very normal. I, even in visits with me, if patients want to record the conversation, you know, they always ask, I say, okay, just so that they can then replay it and…

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digest the information at their own speed. So, you could always ask your oncology team if they're comfortable with that but it is a lot of information. But fortunately, over the course of many visits, we can have the same conversation and add a little bit more depth each time so that you can sort of digest it at your own pace.

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Great. Thank you, Josie. Any other? Okay, great.

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Okay, we'd like to thank our generous donors and grant support from Genentech for making this event possible.

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Thanks to all of you for joining us today and a big thank you to our speaker, Josie Montegaard…

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for her participation in this program. Please complete our event survey and provide your feedback to help us plan for future events.

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A reminder that this virtual event was recorded and will be available on our website along with the slide deck and a written transcript of the webinar.

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

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Join us for our next webinar, Navigating CLL with a Comprehensive Wellness Approach…

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with Dr. Deborah Stephens. And please remember, CLL Society is invested in your long health and you can invest in the long life of the CLL Society by supporting our work. Be strong. We're all in this together.

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Thank you very much.