CLL SOCIETY

Facebook Live Event Transcript
Ask Me Anything – Featuring Jacqueline Broadway-Duren, PhD, DNP, APRN, FNP-BC, and Doreen Zetterlund
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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 complete recording of this webinar is available on-demand.

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Welcome, everyone. I'm Doreen Zetterlund, CLL patient, patient advocate and a member of the CLL Society's Patient Advisory Board.

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We're here today with CLL Society's Facebook Live event: Ask Me Anything where we spend the next 60 minutes answering your questions with a CLL healthcare expert. And we're so lucky today to have Dr. Jackie Broadway-Duren joining us.

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There are no presentations and we encourage you to ask questions on the Facebook page if that's how you're joining us…

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or through the Zoom platform. This event is dedicated to your questions, so make sure you ask them early and we'll try to get to as many of them as we can.

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

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

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The information you post on Facebook will be shared in a public forum, so please don't post anything that's confidential information.

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And without further ado, Jackie, would you please introduce yourself to our audience?

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Good afternoon. I'm so excited to chat with you guys this afternoon.

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Some of you I may know, and some may not, but maybe by the end of this event, I will get to know you at least verbally and on video. My name is Jackie Broadway-Duren. I am a family nurse practitioner, however, I'm also an oncology nurse practitioner. I have a PhD...

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and doctor of nursing practice, as well. And no, I don't just enjoy going to school.

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But I've been working at MDA since 24 years now in the Department of Leukemia and so my specialty area is CLL.

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And I'm just elated to be here with you today and hopefully I can answer your questions satisfactorily…

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and give you some good information. Thank you.

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Great. Thanks, Dr. Jackie. We'll go to our first questions, but it's okay if I call you Dr. Jackie?

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Yeah, it's fine. That's absolutely fine, thank you.

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Okay. Okay, great. How long after completing treatment will my immunity be restored and to what degree as compared to a non-CLL person?

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So, it really will depend on age, that's a factor. And it depends on what treatment regimen that you were treated with.

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But in general, it takes several months and maybe sometimes up to a year before your immune health recovers.

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Blood counts is thought to improve; meaning that if your hemoglobin has been low because of treatment or the platelets have been low,...

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once you have completed treatment, in about six months, those numbers and values should start to return as close to normal.

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Now, I have to tell you, in some cases where persons have been treated with actually chemotherapy...

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it may take longer and sometimes you may not get 100% recovery back on those counts for a couple of years.

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Okay, next question. How long does an IVIG infusion remain in peak force? And is there a benefit in receiving these infusions at less than four-week intervals?

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Yeah, so IVIG usually has a half-life of about three to four weeks…

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and lasts in your system for up to three to five months in most cases.

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So it provides a means of making enough of so therefore, that's the benefit of it. However, no, it doesn't really benefit you to just take it more frequently than a four-week interval.

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Okay, alright. As a CLL patient in watch and wait with a pressing concern with an enlarged spleen, would it be beneficial to undergo a splenectomy or instead to begin treatment to avoid that occurrence? There are no other B symptoms or indications for treatment.

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Okay, well, let me start out by saying, we almost never recommend a splenectomy unless there is some severe problems going on with the spleen and you have severe hemolysis, meaning that the spleen itself may be producing antibodies that are attacking the red blood cells and platelets and causing destruction.

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Outside of that, we do not recommend splenectomies.

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And so while you're in watch and wait, I know this is a difficult time. I hear it all the time, I've heard it for years, I probably would be a little bonkers myself if I had to just watch and wait.

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However, we do not recommend splenectomies just routinely because we know that the spleen is enlarged. It is of no benefit, you need your spleen, it houses extra blood supply.

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Okay, great. Is it common for CLL to affect the lungs and cause shortness of breath and wheezing?

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No, that is not common. Now...

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in cases where patients have, which is rare again, there have been some cases where patients have had some CLL infiltrate into the lung...

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tissue, but that's not common. So no, that is not common for CLL to affect the lungs and cause shortness of breath…

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and wheezing. So, I would suggest in that case that perhaps you should see a pulmonologist and get a full work-up done and see if there may be some underlying autoimmune disease or some other type of problems that may be affecting the lungs.

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But that's not common for CLL, now, there are certain treatments that may predispose you to lung problems but routinely, outside of that, no.

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Okay, this question seems to be maybe related. How common is pleural effusion in CLL patients? And if you could explain what that is, and does CLL cause this?

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Again, generally, CLL does not cause pleural effusions. Now, if you have, many of our patients are, CLL is known to be in an older patient population.

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So many of them have other comorbidities that may be contributing to this but generally, no, we don't just see pleural effusions in CLL.

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Now so, let me explain what pleural effusions are. So, you have two lungs. I'm sure everybody's aware of that.

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There's a lining around the lung that is called the pleura.

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The fact that the hosts, uh you know conceals the lung tissue And so what pleural effusion is, there's a build-up of fluid in that space inside that pleural set. Sometimes pleural effusions can come from infections.

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So, if you, for instance, have been treated with something with the chemotherapeutic or chemoimmunotherapy for CLL, you may develop pleural effusion because of the treatment itself, but not just the disease.

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Okay. Next question here. How can I determine if my fatigue is CLL-induced fatigue or potentially caused by menopause related sleep deprivation or other events causing lack of sleep?

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That is a very good question. I asked myself that day, how can I determine what is the cause of my fatigue?

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But all jokes aside, sometimes you can't differentiate whether the fatigue is CLL based or whether it's menopause.

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If you're menopausal, some of my patients have described this as a double whammy for them.

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We do know that with CLL, particularly in advanced disease stages that the fatigue happens as a result of the autoimmune complications that's going on but I'm sorry, I didn't mean to say autoimmune.

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The fatigue comes because of the increase in cytokine activity with CLL as the disease progresses…

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so sometimes it's hard to differentiate whether the fatigue is coming from CLL or menopause.

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The best thing I would recommend is for you to make sure you follow-up with your gynecologist and maybe they can test your hormone levels and so forth and see if there's any indication that that may be causing fatigue. Now, if you have CLL advanced disease and you have anemia,..

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your hemoglobin is low. Anytime you have a low hemoglobin,..

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less than nine, I would say, or 10,..

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if you normally have a robust hemoglobin of 14 grams as a female and all of a sudden now you're down to 10, you're going to feel more fatigued. Guess why? Because the hemoglobin carries that oxygen component throughout the lungs,..

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I mean, throughout the body and to the lungs and all tissue. If the hemoglobin drops, you have less circulating oxygen. So yes, you're going to feel more tired and fatigued.

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Okay. Is there anything specific that CLL patients can do to avoid getting chronic fatigue? And the questioner says, you know, being told to just deal with it or get yourself moving is not always helpful.

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No, it's very difficult for a patient to understand when you tell them you need to exercise when they're telling you, I'm back on this sofa by 11 or 12 o'clock in the day.

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So, there is some truth to that, however, so the first thing you want to do is make sure that you're well-hydrated, that you're drinking lots of fluids and try to stay active, even if that means walking to the mailbox and back to the house. If you can do that a couple of times a day, that will also help you.

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The other thing you want to do is make sure that your primary care or your oncologist or whomever you see frequently, checks your iron stores to make sure you don't have an iron deficiency on them or a B12 deficiency and also check vitamin D levels and make sure you have adequate amounts of vitamin D…

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in your body. So those are some things but just stay well-hydrated…

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and try to modify your diet. Believe it or not, foods that are high in fat and high cholesterol and those things as they break down, they weigh the body down and that will cause more fatigue.

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So, those are some of the tips that I can recommend to you.

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We've got a little section of fatigue here, of questions, so we'll just keep going. Short of getting a boost in energy on two days, I inject testosterone, fatigue plays me, plagues me constantly. Is there anything I or the oncologist can do to lessen this occurrence?

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No, basically, I would recommend the things that I just talked about. The other thing that always has to be considered, so what I found out in my practice, I did my dissertation on autoimmune diseases, so I found out since that time that…

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several patients in my practice actually had an underlying autoimmune disease.

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So, I'm not saying everybody has autoimmune disease, but what I'm saying is that may be an avenue to explore.

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If you have auto, any kind of autoimmune disease and there are many, but the ones I've seen commonly in my practice are rheumatoid arthritis, sarcoidosis, lupus, those type things.

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They can draw inflammatory markers and see if those are elevated, then maybe you need to be referred to a rheumatologist, but that's the other thing. Exercise as best you can. Yoga is a great exercise.

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And then just if, you know, some therapists or at gyms and so forth have relaxation classes where they teach you relaxation techniques. All of those things may help to improve fatigue.

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You have to search for a number of issues. I know I went through really intense fatigue and that was part of the start…

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of my reason for my treatment. And we checked everything, the thyroid and it everything. So you kind of check them all off the list. And once everything is managed, then you still got fatigue and then you just have to try to find a way. And I do find me a sweet spot in exercise,..

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not too much, not too little, just sort of a sweet spot is helpful.

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You don't want to, one thing I want to point out is, you don't want to overtax your body because I had a patient who told me they were trying to run 10 miles a day and I said, that's just not reasonable, that's why you're even more fatigued.

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But do a reasonable amount of exercise. And I think yoga and meditation exercises also may be helpful.

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Yes. Is there a connection between having a lower than normal range LDH, which is lactate dehydrogenase,..

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and my experiencing increased fatigue?

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Well, actually, what the LDH is, it's an enzyme and it elevates outside of cancer. It elevates with muscular insult, like if you have an injury to the muscles or things like that…

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so that can certainly increase your LDH level. So, I guess, but as far as CLL, as the LDH increases, we use it more like a tumor marker, as it increases, that tells us that your disease is likely progressing.

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So yes, that's the correlation then, it would indicate that if you have increased disease, you're going to likely have the fatigue that accompanies it.

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Okay. Does having CLL or SLL increase the occurrence of having cold sores and if so,..

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how and why?

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Okay, so cold sores There are a few exceptions, but basically those are herpes, the herpes simplex virus...

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Type 1. Oh, and so let me give you just a brief lesson on the physiology of why your immunoglobulins are lower and why these virus, these opportunistic viruses just kind of get in there because as CLL cells when they…

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are produced in the bone marrow as they go through that maturation phase...

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and they reached maturity, at that point, some of those good lymphocytes, B lymphocytes, should go out into the plasma and become immune globulins…

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or memory B cells to remember if, oh, she's had that before, so let me start to work against it.

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The problem with CLL is as the CLL, the B cell matures, and reach that level,..

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the cells, they don't die off. They just keep circulating and circulating and circulating and they're being nourished by these nurse-like cells.

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So, since they just continue to circulate and don't die off or continue on to that final stage of their life cycle, which is to go into the plasma and become immune globulins,..

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you're going to have a lesser amount of circulating immune globulin. The main one that we monitor is the IgG level.

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So, when you don't, when you have a lesser amount of those immune globulins...

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and your immune system then is going to be somewhat suppressed, so these opportunistic viruses like the herpes simplex and zoster and others,..

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Epstein-Barr and several others, then they have the opportunity then to come and create problems. So, yes, there is a correlation between a low immune globulin and those cold sores.

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The next question in that same vein is, do you have any recommendations on how to treat cold sores other than using valacyclovir? The questioner says this medication doesn't agree with the questioner, causing nausea and stomach aches, but that's also for shingles...

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correct?

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It is for shingles, but it's used in much, much higher doses…

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for shingles. Valacyclovir or Valtrex, there are others in that class, there's Zovarix...

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and famciclovir, acyclovir, any of them, they're all the same class, just manufactured by different companies.

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So generally, if they are external cold sores like on the lips or the uh, the crack or just inside the nostril, I generally would give my patients Zovarix ointment…

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and you can just put just a tiny amount on a Q-tip and just dab that place about three or four times a day…

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and it does have a healing effect in most cases. If the cold sore does not go away, you probably need to see a doctor and make sure that that's all it is.

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Okay, next question. Do you know what causes purple discoloration on the scalp,..

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questioner is bald, and on the face, on or off on those with CLL?

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Yeah, those purplish discolorations, sometimes it's because you have a lesser amount of functioning platelets…

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and that's called purpura or large bruises. And it's caused when the blood vessels under the skin rupture or break and just tiny bits of blood are leaked out into that, and just under the skin in that space.

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So, um, particularly you may see this in patients who are treated with the BTK inhibitors…

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because you have some ineffectiveness of the platelets for patients who are on those drugs. So yes, they may see these large purplish discoloration or bruises on the scalp, on the face,..

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the arms everywhere. Go ahead.

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And those are different. Oh, I'm sorry.

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So I just said, I don't want you to be alarmed because it's not uncommon to see those bruises with CLL.

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And that's different than petechiae, right?

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Yeah, petechiae are just tiny, tiny, tiny bruises. Like somebody just took a, a pin and just, just these tiny little dots all over the place. It's the same exact thing except they're smaller. It's just little tiny capillaries on the skin that pop and you have little tiny bleeds going on.

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Okay. Is post-nasal drip a known side effect of ibrutinib or is it a symptom of CLL?

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And can...

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and can having low IgG cause this?

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It can be a side effect of ibrutinib.. I don't see it…

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as often, but I have had patients who have noticed, and it is in the early clinical trials, it was noted as one of the possible adverse effects of this drug. Yes, this is possible...

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with ibrutinib. Having a low IgG,..

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no, I don't think it, well, indirectly, because if you can't fight out viruses, then you do know most of the time they're just different viruses that cause the rhinorrhea or runny nose and stuff, uh so and there could be some correlation…

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between the two.

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And isn't it also that we're more prone to allergies? I mean, I feel like I'm more prone to seasonal allergies…

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maybe because of my CLL or maybe just because I'm getting older.

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That's it.

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No, it's probably likely associated with the lesser amount of circulating immune globulins.

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Okay. The questioner has been recommended to take zanubrutinib as the next treatment for returning CLL…

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but the potential side effects are concerning. What is your opinion of the side effects for this treatment versus other options? The questioner is Trisomy 12 and was treated with obinutuzumab in the past.

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Well, to some degree, all the BTKs - the ibrutinib, which was your first generation BTK,..

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second generation acalabrutinib and zanubrutinib, and now the pirtobrutinib, which has a little bit different mechanism of action -but all of them has potential to cause hemorrhage,..

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bleeding. The ibrutinib, I think, probably more so than others because we had patients on that drug for years, so we saw it clinically.

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Increased bruising, you'll see that with all of the BTKs to some degree;..

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weakness, joint and muscle pain is common for all of them.

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And the zanubrutinib actually, has a little bit better side effect profile than some of the others.

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There's a lesser likelihood of atrial fibrillation which was not uncommon with ibrutinib.

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We've seen this on with acalabrutinib but again, it is a BTK inhibitor, so it may be able to cause some cardiac flutter and those type things. I would say of all the BTKs, it probably has a little bit lesser side effect profile.

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Okay, how does the prognosis differ for those diagnosed with CLL at a younger age versus those diagnosed after the age of 50?

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Well, clearly younger people are in most cases healthier and so they don't have a lot of the comorbidities that you would have as older patients. When I see patients in clinic, the average age of CLL being around 70 or 72.

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Generally, they're going to have some other type of health problems like hypertension or hypocholesterolemia…

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or they may have already been on medication for some type of heart problems or fluid retention and different things, congestive heart failure. So of course, people who are younger generally don't have a lot of comorbidities. So yes, they are going to have a longer life expectancy.

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And from the, uh, the studies we don't see an extreme lot of young people with CLL, but we've seen more over the last several years , than previous years. So they generally have a better overall survival.

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Okay. Do you have any recommendations on how to best manage the risk of secondary malignancies when being on O and V, which is obinutuzumab and venetoclax, and is age a factor in contracting secondary cancers?

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Absolutely. So, what we recommend, I actually run survivorship clinic for CLL,..

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here at our facility, and my main focus when I see those patients in survivorship clinic is whether they're in survivorship or whether they're in active treatment, we always encourage them to get health screenings.

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Just because you have CLL and you're getting therapy, you still need to get your mammogram.

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You still need to get the PSA levels in prostate evaluation according to the American Cancer Society. I know that they are making the guidelines now show the cutoff at younger ages than they have in the past but get those screenings.

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An ounce of prevention is better than a pound of cure. So prevent...

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and what I'm referring to is referring to I can't tell you how many patients I see who come in with skin cancers. It's very prominent in CLL.

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Very high incidence of skin cancers. What you don't want to do is keep exposing yourself to the sun without the proper protection meaning some very good sunscreen or those long sleeve clothing you can wear that blocks sun rays. Always wear a hat when you're outside, men in particular.

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Because skin cancer is very high, you don't want to end up with the melanoma...

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which can be metastatic. So, wear the proper sunscreen, try to eat appropriately.

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A high-fat diet is not only contributed to breast cancer and other cancers.

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So nobody loves Pappadeaux's more than me...

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but there are just some things on the menu at Pappadeaux's that are healthy.

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So just try to make healthy choices in food. Make sure you're eating green vegetables and fruit…

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however many servings that, you know, you have available to you during the week. So, those are the things that you can actively do to prevent. Now, some things we have no control over…

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but get those screenings. If you're a smoker or you know you have a history of lung problems or something, make sure you're getting those serial chest x-rays and just follow-up…

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as scheduled with your primary care providers.

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I have to admit I am a project manager by trade, is one of my trades and I keep a little spreadsheet because, you know, we're all living so fast. It's like, I think I had my mammogram or I think I did have a skin check and it's, it's good to keep track of that stuff so you can prompt yourself to make that appointment.

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That's absolutely true. And one of the main ones, other than skin cancer is colon cancer.

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And I know that is directly linked to high-fat diet. So just think about that as you're making choices for meals.

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For sure. Can younger patients on O and V, again, obinutuzumab and venetoclax, expect a longer remission versus those who are older with this treatment regimen?

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Again, because just the fact that they are younger and healthier, that is theoretically, they should have a longer remission. Now, considering the fact that um, we probably don't have the best data in the world on tracking younger people because CLL is not a young person's disease, so the jury may be still out on that a little bit, but the sources I've read, they say yes...

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because they have better health overall so they're going to generally have better outcomes. However, patients who are unmutated, they may still enter into you know the outcome being about more of an even keel.

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Yeah, I was going to ask, would markers uh, play into that and to the length of remission or do we not really know that yet because these medications are so new?

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Yes, that's right. They're new. And again, we don't have a huge, huge population of younger people.

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Well, I guess it depends on how you define younger.

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Yeah, 50 is the new 40, right?

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Yes.

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Are there impacts on CLL, good or bad, if a menopausal woman uses hormone replacement therapy?

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I have not found that to be the case. We have many of our ladies who are on hormone replacement therapy.

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Um, that has not been known to be effective to my knowledge….

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in the past.

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Okay. Does taking a high dose iron supplement such as 125 milligrams a day in stage zero CLL, no other symptoms, would that iron be helpful or could it cause issues in the production of healthy blood cells on the bone marrow?

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Okay, yes, that's a very interesting question. Some people think that taking iron a little bit of iron, a little bit of B12, and a little more is better.

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But if you have normal iron stores and your body is making the amount of iron it needs, you don't need to add additional iron.

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You only need the iron if you have iron deficiency anemia.

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And that's easy to find out, you know, the primary care doctor, all they need to do is do an iron panel and that'll tell you whether your iron stores are adequate. If they are, you don't need to add iron. You can,

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unless you’re people where you can have too much iron build-up in the body and then you'll have to take medications to bind with iron to try to get rid of.

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So, no, I wouldn't recommend taking iron supplements unless you need them.

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Okay. Will you explain how having CLL or SLL can affect other major organs? If so, are there other tests I should receive to help ensure those organs are functioning well?

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CLL, you know, as you know, it's a lymphocytic disease and so it can be in lymph node,..

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here, there, and everywhere.

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CLL doesn't metastasize as people think solid tumor cancers. It's a blood-borne disease so it's generally going to be in the spleen or in the lymph nodes or in the bone marrow, of course, in the blood. So generally,..

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they're the only organs that is known to affect is the spleen and the liver.

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And so that's why every time you come in for an exam, I know in my clinic, we always examine the liver and the spleen.

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Because it's very important to find out early on what those meant, whether that spleen is getting more enlarged or the liver and try to do early intervention there so those are the two organs that we know CLL...

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routinely affects.

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Okay. Have you seen CLL go into remission after completing R-CHOP treatment for diffuse large B-cell lymphoma and if so, how long would it last? The questioner is in remission after CLL transformed to DLBCL...

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and the oncologist is saying the CLL will probably return.

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Well, there's always a chance of CLL returning.

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We are using R-CHOP now for patients who transform, what we call a Richter's transformation.

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We're using R-CHOP now in addition to venetoclax. But yeah, we've seen some good long-term remission with those patients. There's no magic wand that we can wave to tell you exactly...

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how long that patient is going to, but we try to predict that based on all the prognostic factors, you know, whether they had a 17p, most patients who transform do, and most of them are unmutated.

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So, it's so many different factors that you have to look at to determine that.

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One patient I can think of right now, has been in remission over five years who transformed. He had one of the worst Richter transformations that I've seen. He was very, very sick...

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and he has been in remission now for over five years...

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and we see him annually. And he looks wonderful, like he's never even been sick before.

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Whereas we have other patients who have gone through Richter and have taken the same treatment and maybe wasn't as successful, maybe two years remission. So, it varies. There's no set number, it really is individualized.

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But there's a little, there's hope there so that that's good, good to hear those stories.

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Yeah.
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For lactose intolerant CLL patients, what would you recommend best to avoid osteoporosis?

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Yeah, I kind of, I've kind of debated over that question. I reviewed the literature on that. You know, orange juice is a high source of calcium as well. Certain green leafy vegetables are high sources of calcium.

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I attended a lecture by a cardiologist regarding calcium intake.

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And so, it seems to be mixed reviews in the literature whether taking calcium tablets are recommended or not. But I guess in the case of someone who's lactose intolerance, there may be an option to take calcium supplements. What you…

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can also do as an alternative is to use lactate and then you know, drink milk or yogurt or whatever cheese. Those are all great sources of calcium.

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But if you use lactate, I know patients who have successfully been able to tolerate milk products...

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with lactate as it prevents that same type of reaction you would see.

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What are current methods to improve the immune system? The questioner says the immunoglobulin A is 24 and immunoglobin M is 23.

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Oh, yeah, we don't put a whole lot of focus on those immune globulins. The main one that's going to boost your immune system is the G.

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IgM.

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So I'm not, maybe I didn't fully understand the question.

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So, would you restate that for me?

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Okay, sure. What are the current methods to improve the immune system?

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Okay.

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Oh, um, in patients who, what they always try to teach patients is that just because your immune globulin levels are low doesn't mean that you always, that your immune system is not functioning.

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You’re still going to have some function. And we don't even treat low immune globulin levels necessarily. We don't treat by numbers.

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Just because your IgG is low, just about everybody with CLL IgG level is low.

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So if a person is having a recurrent respiratory infections...

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and especially during the winter months, then we do recommend and prescribe for them the IVIG infusions.

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Other than that, you know there are things, vitamin D. Always make sure you get your vitamin D levels checked. You'd be surprised.

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So CLL patients, some of them tend to avoid the sun because of the risk of skin cancer.

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So guess what? When you're not in the sun, you're not getting that vitamin D.

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Yeah.

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And so, you may actually have a, that can attribute to a lesser immune system, supplements, and this is strictly a recommendation, I encourage patients to take zinc…

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because that is an immune booster as well. Vitamin C.

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And try to do it naturally with supplements such as that…

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and, you know, plant-based vitamins if you can.

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The autoimmune globulins are important. And they all have their function in the immune system.

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But the one that covers the immune system for long-term protection is going to be your IgG.

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So, if we try to replace all of them, you know, we probably couldn't, the patient probably couldn't afford the cost because just to get IgG...

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or IVIG is very expensive. And for any patient out there that has gotten that infusion...

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and had problems with your insurance company, you know how expensive it is.

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So, we do know they all play a part in immune health...

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but the main one being the IgG and so that's the one we try to focus on.

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This next question, I'm going to try to paraphrase a little bit.

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The questioner is a caregiver for a CLL patient who's on watch and wait.

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He was first diagnosed in 2021. His white blood counts have been hovering at relatively low levels for about two and a half years.

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He's seeing a well-known CLL specialist and was originally being observed every three or four months…

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and then six months and now the doctor says he has no indications of aggressive disease.

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And the doctor says just once a year and the caregiver is concerned. Does that seem right?

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The watch and wait, you know, makes us all crazy. And it. what are your thoughts?

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So what we look at, it is difficult for the patient...

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and, you know, we try to explain and reassure them as much as possible.

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If your counts, if your white count hasn't doubled in six months or less,..

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then you're probably okay. By the same token,..

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if you come into the clinic and you say your white count is maybe 25,000, And we say, oh, everything looks great,...

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you can rest assured that to make that decision, we've looked at that FISH test…

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to see if you have favorable prognostic factors or whether you have a 17p, we do the next generation sequencing where we look at all these different genes, where we look for mutations and try to predict if you have mutations in genes such as…

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Notch one or TP53 and ATM. All these things tell us you're more likely to progress. So yeah, we may have you come back in six months.

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But if you have good prognostic factors or your FISH test is negative or at worst you have a 13Q deletion,..

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we're good with that. And if your counts are not doubling and you come into the clinic and I ask you...

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are you having drenching night sweats? How fatigued are you? I don't ask CLL patients, are they having fatigue? I ask them what level of fatigue they're having.

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Oh, and I usually give them a zero to 10 scale with 10 being the worst.

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That helps me to judge there, whether this patient is more likely leaning towards needing something or not. So, it's not uncommon for us to have a patient come back in one year because we've looked at all those different factors and not just the white blood cell count.

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And I think especially if you're seeing a CLL specialist, you know someone who's very familiar with that, it's not, you know, and also for us to educate ourselves on those B symptoms.

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But…

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If you're not having those B symptoms, then you're probably okay.

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Yes.

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In terms of fatigue, I know I dealt a lot with very deep fatigue where I would make a salad and then I was too tired to chew it.

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That's a lot of fatigue, but that's different than just, you know, you rake leaves and then you're tired.

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There's a reason for it. So being aware and educated

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Right. It is safe to wait a year as long with all, everything being within the range that we needed to be in.

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Okay. A 78-year-old questioner says, can acalabrutinib create weight gain? I've gained about 20 pounds in two years I've been on treatment and it's located in my abdominal area. I eat well and I exercise.

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We did see that more so with the ibrutinib. But again, since it's the same class of medications,..

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yes, we have seen some weight gain. And, and maybe it may be attributed to the fact that you feel better so you're eating more than what you really realize that you're eating.

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So again, I would encourage exercise, And you know,..

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if you're getting into a remission with acalabrutinib, then work on, you know, the weight. As long as you're not retaining a lot of fluid where you have a significant swelling and edema in your ankles and feet and your hands, then there may be another underlying problem going on.

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And then we also have to realize as we get older, our metabolism is slowing down. So, but yes, I have seen some patients uh, develop weight gain while on the BTK inhibitors

as well as you should also keep close check on your blood pressure. If you're gaining weight, you definitely want to monitor the blood pressure.

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Okay, 65-year-old woman who has been on venetoclax as a second-line treatment for about 13 months...

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senses some hair thinning. Is that usual?

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If we have seen that occur, it's not as common as you would see with the bruising with the BTKs, but we have had some patients complain about hair thinning with venetoclax.

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Now, in the research studies that were done on venetoclax that is not a high percentage of that…

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that was shown in the clinical trials, but it's possible. And so again, with venetoclax, you should be hydrating very well. And so that in itself will help keep your body moist and may help with the hair loss but maybe you can uh,..

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you know consult a hairstylist or someone that maybe offers some advice to you.

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Okay, next questioner says, I've just been diagnosed with CLL. At this point, no treatment. I'm concerned about infections and viruses. Several things I've read said live your life as normal but my normal is often being at church or church activities where there are big crowds. So, is it wise to go or should I not?

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Okay, number one, you may want to have them check your immune globulin levels…

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and see if the IgG level is you know, in a reasonable range.

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Some people with CLL do have really good IgG levels so that would be one thing I would suggest.

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Secondly, it's kind of like, you know, all these viruses are out there.

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So even as a healthy person, myself not having CLL, I'm always conscious of what's going on around me.

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If I know I'm in a large crowd and there's 10 people around me coughing and sniffing and snorting, I'm going to kind of remove myself from that area…

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or put a mask on if that's what I choose to do.

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So, it's some things, you know, you just have to figure out what works best. If you are one of those people that gets sick every time somebody sneezes on you, you probably want to avoid being in those kind of situations.

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And I also at that point, I avoid the snacks, the snacks and all of that. I stay away from that in a room full of people who are coughing because you just, you don't know, you don't want to put that into your system.

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Yes, I tell my patients all the time. Just, you know, find somewhere else to eat, stay away from the Golden Corral because you don't know who just coughed, sneezed, or whatever over the food. They're picking up the ladles. People don't always wash their hands.

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So it's not, that was just an example, buffets in general, you always have to be mindful of that. I know every time I go into Whole Foods, they have this open food bar with salads and hot foods. And I'm thinking…

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there's no way I'm going to eat anything off that bar because I see people passing by they're coughing all the time so, you know.

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Yes, I'm even careful with like, shared utensils or the soy sauce container and all of that. So, I've always got wipes in my purse.

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Next question. I was diagnosed two years ago at 55. My mother was diagnosed last week at 79.

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What does this mean for my children? The little information I found says it's more likely to be generational in women and that later generations would get it younger. Is that true?

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I have seen that bear true in our clinic. I've been in leukemia In CLL for almost 24 years.

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I have seen multiple families with sets of people in the family. I've seen twin brothers, sister brother, twin sisters, I've seen grandfather son grandson, you know, so yes it is familiar. I think the Mayo Clinic did a study on familial transfer CLL.

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I don't know that they had any exact conclusions, but I've seen it many times in my practice.

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We have even right now, we have siblings that are coming here and they have CLL.

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What it means for your children? You know, we have genetic clinics and stuff now where people are maybe getting tested to see if maybe there's some gene that can predict the likelihood that they may develop this or not.

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Now, I'm not a geneticist, but we do have a genetics clinic in our leukemia departments. And I mean, you can anywhere.

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Most places now have geneticists available.

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Well, and I think part of that too is once you have CLL and you have all the relatives that have CLL, you know what to look for.

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Exactly.

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So, you know, with the younger folks, when they're getting their annual physicals for school or whatever, you're watching those things and uh, are aware. I know when my SLL was diagnosed, it was just a lump on my neck and I was having cervical problems so we thought it was a spasm.

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So, I was sent to physical therapy and they were pressing on it and it wasn't going down.

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So, I had some imaging and that's what brought it to light. But it's like, if you're aware that a lump could be that, then you get it checked out…

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instead of going a certain more circuitous route to, to uh, for diagnosis.

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Yeah, so because we get many patients who come into the clinic as new patients…

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and when I look at the labs, I go back and trend their labs for the last four or five years.

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They've had elevated white count all this time, and the primary care, in most cases, I mean, they're primary care providers, so they don't, the light bulb doesn't go off if you have a persistent elevated white count.

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They figure it's an, infection or something. But with that being said, if your kids are exhibiting any of these symptoms or if your children, maybe early 20s, early 30s, and they start complaining about swollen lymph nodes and you know there's been two generations in your family already that had CLL,..

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you know, it behooved them to go ahead and, you know, maybe get checked and make sure that it isn't. And if it is, that would be great. You find out early.

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Yeah.

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Okay, next question. Can my CLL diagnosis morph into another type of leukemia or cancer?

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If so, what are the percentages where this happens?

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So again, we have to think about Richter’s transformation. Generally Richter’s transformation, I've seen two patients In the last 10 years, I think…

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that have come in with a Richter’s transformation from the start.

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But that's unusual. Generally, when it morphs into that, it is patients who've relapsed, they've already been treated and now they are coming back with relapsed disease. And for whatever reason, it just accelerates usually because they have that 17p or they have a Notch 1mutation…

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or some mutation that drives this process.

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Usually if it's going to morph into another type of blood-borne disease, it will be the lymphoma, the diffuse large B-cell lymphoma, and that is called the Richter’s transformation.

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We have had patients who I don't know that their CLL morphed into this…

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but we found that they had a concurrent diagnosis of Waldenstrom macroglobulinemia where you have too much IgM and so when patients come in, that's why every aspect of that lab is looked at.

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When we look at those immune globulins, we don't glaze over them and take anything for granted.

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And the first indication of that may be elevated protein on your regular chemistry panel.

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If I see that, I'm going to start ordering, you know, tests to rule out so those are the things that we do see sometimes that occurs in patients with CLL.

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And on rare occasions, myeloma. But that is rare.

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Okay. Is there an absolute white blood cell count level where treatment is recommended or is it more dependent on symptoms and other components in the CBC?

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And they've heard about prognostic, doubling time, that that's kind of an indicator.

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Yes. So that is an excellent question. I get asked that all the time. No, we don't treat people based on a certain white blood count.

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We've had patients with as close to 300,000 white counts who still chose not to be treated.

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Uh, but they said they weren't having any fatigue or night sweats and that's all we can go on if they tell us.

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So, by the same token, you may have somebody with 25,000 white cells and they are having drenching night sweats and have, you know, enlarged lymph nodes to the point of maybe pressing, you know, and it's uncomfortable for them...

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and they may need to be treated. I don't know how many of you have known Dr. Michael Keating, but that was my first mentor and physician I work with in CLL...

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and, you know, there are times we treated people, I would say back in the day, just because they were symptomatic.

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Not so much now, but yes, many factors. The doubling time, if it's less than six months,..

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you know, if you're having these heavy sweats, if you look at that CBC and you notice those platelets and the hemoglobin are trending down.

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Then yes, those are all indications for us to consider treatment for that patient. So, it's not based on the white blood specific, white blood count. Every patient is individualized. There's no one size fits all.

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And I've heard trending too even one lab that's bad is not a trigger for treatment. It's a trend, right?

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Yeah. Yeah, because if you just had a cold last week…

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and it's in your lymphocytes are ramped up because it's trying to fight off that virus, which is most colds are viral,..

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then that's not a time for you to determine whether that's an indication for treatment. It has to be a trail where we see a steady increase in that blood count over time. And so when we say a double in time, we got to start somewhere and figure out where…

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the white blood count has accelerated and doubled.

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Okay, I think we have time for one more question here. Is it common for CLL patients to have calcium deficiencies?

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That's a question I really don't know the answer to.

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I don't know what the link is or correlation for calcium deficiency in CLL.

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That is a question I'm going to have to research that…

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because I just don't know. Most of my patients do not have calcium deficiencies. Matter of fact, they have just the opposite, many of them have too much calcium...

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because older patients tend to overdo it with calcium supplements. So, I've not known that to be known the case, but I certainly will research and then find out the answer to that and I'll be happy to share my email and you can email me and I'll be happy to expound on that further for you.

01:03:13.000 --> 01:03:29.000
Well, that's very kind of you, Dr. Jackie. So maybe we can get one more question. Diagnosed in December 2024, lymph nodes are swollen throughout my body. Should I be worried about this without any of these symptoms?

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Oh, it depends on how enlarged those lymph nodes are and where they are. If you have nodes in your neck and they're so huge you can barely have mobility of your neck and move your neck around or for instance, I have a patient who came in with nodes so large, it was the size of oranges in his axilla armpit.

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So that affects your ability to even do your daily activities and routine.

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So having the lymph, we all have lymph nodes and most of us have some swollen lymph nodes depending on whether we got allergy symptoms or whatever.

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So just having the nodes, it should not be a pause for major concern. But if those nodes keep getting larger and larger and you're seeing more of them, yes, you do need to be evaluated.

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Okay, great. Dr. Jackie, this has been great. I hope that you come back and join us again. Before we close this program, do you have any closing thoughts for our audience?

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Just some general hopeful.

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Yes, I would like to share that I've been working in CLL since before the era of the BTK inhibitors and when they were still using chemotherapy and immunotherapy and so I've seen it from that point of view.

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But what I can tell you now, this is the era, if you're going to have CLL, this is the time because they have the best treatments available now.

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So if you, maybe the person who had the obinutuzumab and venetoclax, I believe it was,..

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they have such great treatments and we still have ongoing research now with even newer formulations of these drugs so this is the best leukemia to have if you're going to have leukemia right now. I can tell you that. The treatments are only getting better. And for those on watch and wait,..

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you just, you know, make sure that you get in a good group of support group of people so they're not talking to people whose all doom and gloom. You want people that's going to encourage you.

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And if it's a major concern, talk to your healthcare provider.

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Well, thank you so much, Dr. Jackie, for your time and expertise. We're so very grateful for your participation. You really answered so many questions for us. We really appreciate it. And I want to thank everyone who joined us today. And we'd also like to thank our generous donors to CLL Society and grant support from Genentech for making this event possible.

01:06:04.000 --> 01:06:11.000
A few brief reminders, if you're a Facebook user, please remember to like and subscribe to the CLL Society Facebook page.

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Please complete the short event survey linked in the comments section on Facebook and will be shared with everyone who registered through Zoom as well.

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We really want to hear your feedback and we appreciate your time in completing the survey.

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Please join us on March 26th for our next webinar, CLL 101: Biology, Symptoms and Diagnosis, which will be geared toward beginners and people new to learning about CLL.

01:06:38.000 --> 01:06:44.000
If your question was not answered today, please send it to our Ask the Expert email service.

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This is a free service and can be found on the CLL Society website under Programs and Support.

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Remember to follow the CLL Society on Facebook and other social media platforms.

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And lastly, the CLL Society has invested in your long life. And you can invest in the long life of the CLL Society by supporting our work.

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Thank you.

01:07:16.000 --> 01:07:17.000
Thank you. I enjoyed it. That was a great, great discussion.

01:07:17.000 --> 01:07:23.000
Thank you, Dr. Jackie.

01:07:24.000 --> 01:07:31.000
Yeah, thank you. So many good questions answered and I think you put a lot of people's mind at ease with, with your calm demeanor and your longevity in this industry and all that you had to share with us today. So, thank you so much. It was nice to meet you.

01:07:31.000 --> 01:07:47.000
You as well. Have a good evening. All right. Bye-bye.