Webinar Transcript
Beyond Your CLL Diagnosis: Comprehensive Health Management
September 17, 2024

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This text is based off 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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Welcome to today's webinar.

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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.

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

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Thank you.

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Thank you, Robyn. I would like to welcome our audience to today's event.

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I am Terry Evans, a 24 year CLL survivor…

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and director of the CLL Societ's Support Network.

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We are joined by nurse practitioner, Amy Goodrich at Johns Hopkins, Kimmel Cancer Center.

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We will be answering questions from the audience at the end of this event…

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so please take advantage of this opportunity…

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to ask your questions in the Q&A box.

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

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The information provided during today's webinar is for educational purposes only...

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and should not be considered medical advice.

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For any personal health or treatment questions, please consult with your healthcare team.

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Please note that while the CLL Society may have its own opinions and policies,..

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our speakers may offer differing viewpoints, especially regarding the management of CLL.…

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and its complications.

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Now it's my pleasure to welcome Amy Goodrich.

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Good morning. Thanks for being with us here today. So we are going to be talking about beyond your CLL's diagnosis a comprehensive health management.

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So today, with our treatment advances, the majority of patients with chronic leukemia will die of non-CLL clauses, such as second cancers, vascular disease, infection, stroke, lung disease, renal disease.

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Essentially, other medical problems that are unrelated to their CLL.

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This is due to an improvement in survival for patients with CLL, our improved therapies for patients with CLL, and so many of these conditions that are not related to CLL and their risk factors can be identified with routine screening, and possibly prevented or improved or slowed down.

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So equally as important…

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as our CLL therapy to improving survival is the need to address overall health for patients with CLL.

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So let's start with infection.

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So as a blanket, people with a CLLLL diagnosis are at higher risk of infections and higher risk of severe infections.

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Even though most patients with CLL have an elevated white blood cell count and white blood cells fight infection, those white blood cells do not function normally.

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And so then, people develop infections. In addition,..

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up to 40% of people with CLL will have low immunoglobulins. Specifically, IgG levels up to three years before a CLL diagnosis. And I'll talk about that in a second.

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And then others will develop a low or lowering IgG level after their diagnosis from both the disease and from the treatment of their CLL.

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So what is a low IgG level? Technically, it's called hypogammaglobulinemia. But IgG is an antibody...

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type of protein that is produced by the immune system. It fights germs and it protects us from bacterial and viral infections. The thing about IgG is that it is their specific to a certain germ or infection they remember. So this is what prevents us from getting the same infection over and over again, because IgG,..

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the memory portion of it, allows our immune system to quickly attack a germ or an infection that we have been exposed to in the past. So, this is a big part of our immune system.

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These IgG levels can be monitored with a blood test. And when IgG levels are low,..

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people are at more risk for infections.

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And most commonly their upper respiratory tract infections, like sinus, bronchitis, pneumonia.

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And in addition, because IgG, creates memory, vaccine responses tend to be poor because they're not, they're not functioning normally to create that memory after we get a vaccination.

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So people with CLL and a low IgG levels and recurring infections may have IgG replacement therapy recommended. That therapy can be given intravenously in an infusion center or subcutaneously administered by the person at home.

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So how can we reduce infections for patients with CLL?

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So if you are on therapy, if you have received therapy in the past six months, if you are receiving IgG replacement therapy, you really need to be discussing immunizations with your oncology team. I would encourage everyone to discuss immunizations with their oncology team in general. But if you're not being treated, you haven't been treated, your IgG is normal, it is really most likely that your...

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team is going to recommend that you follow CDC recommendations for immunizations and boosters. And so that includes an annual flu vaccination,..

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it includes that initial COVID-19 series and all boosters as they become available,..

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the shingles vaccine...

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is recommended for everyone over 50, plus those 19 and older with immunocompromise. And technically, everyone with CLL has immunocompromise.

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The RSV is recommended for everyone 75 and older, plus 60 and older with increased risk for severe RSV and again, that includes people with CLL.

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Pneumococcal vaccine for age 65 and older, and then DPAT which is diphtheria, tetanus, whooping cough boosters every 10 years.

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And this is not only important for…

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a person with CLL but those around you as well, because if you can't get vaccinated or you have a limited…

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response to a vaccination, you are at risk for getting infected from those close...

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to you, those you were in close contact with. So you, and you know, folks that you're in close contact with should be following these recommendations as well.

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What are other things we can do to reduce infections? So some of these are really common sense: handwashing, hand sanitizer. And I feel like in the post-COVID world, we're all much better about this than we were in the pre-COVID world.

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Masking in crowds and avoiding crowds when rates are high. So you've got to know your infection rates in your area. If you're going into a high risk area, you know, really considering masking in crowds is a good idea.

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Also, knowing your blood counts, knowing your IgG level, those are really important things as well.

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Reporting fevers, shaking chills, any signs or symptoms of infection.

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And then if you do have symptoms, test or be tested for COVID-19, for flu, for RSV based on the symptoms that you're having. For COVID-19 and the flu, there are medications that can be given…

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to reduce the severity and the length of time that that infection is active. So, it's important to test so that you can be treated.

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Autoimmune complications. These are another relatively common issue in patients with CLL.

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They impact about a quarter of people with a CLL diagnosis.

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And what autoimmune complications occur is when the immune system mistakenly attacks normal cells or tissues. And again, you've got lots of white blood cells normally but they're just not functioning normally.

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And so autoimmune complications are common and people with CLL due to this immune system dysfunction.

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The most common autoimmune complications...

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include autoimmune hemolytic anemia and immune thrombocytopenia, so low red blood cell count and low platelets from autoimmune disorders. There are a few other very rare ones. But it's, it's these two that are the most common autoimmune complications in…

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people with a CLL diagnosis.

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So, treatment of autoimmune complications typically includes prednisone, which is a steroid,..

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intravenous immunoglobulin, cyclosporin, rituximab.

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And then specifically for ITP, or that immune thrombocytopenia, TPO agonists can be used. Those are similar to growth factors.

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And then, if autoimmune complications are not well-controlled with the typical options, CLL directed therapy is recommended. So sometimes just treating the underlying CLL, even if it's not particularly active...

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is what is needed to control the autoimmune complication.

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Secondary cancers is another…

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issue in in patients with CLL. And so these are cancers that are unrelated to the CLL, we're not talking about transformation of the CLL to a more aggressive form of lymphoma.

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But in in people with a CLL diagnosis,...

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there is up to 63% higher risk of developing a second malignancy than somebody of the same age and sex as you in the general population without a CLL diagnosis. So second cancers are very common in patients…

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with CLL. In general,..

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anyone with a cancer diagnosis is more likely to develop another malignancy in general, because once your immune system misses one cancer, it's most likely that it's, it has a higher risk of missing another cancer. Our immune systems are supposed to get rid of cells that don't look right…

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so once you have one malignancy, you're at higher risk for other malignancies. But in CLL this is compounded by the fact that we know that your immune system is not working correctly.

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So those at highest risk of second malignancies are those who have received chemotherapy, male, between the ages of 18 and 69. But this is definitely a risk for every single person with a diagnosis of CLL.

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So what are these second cancers?

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So the most common second cancer in patients with CLL are skin cancers. They tend to be non-melanoma skin cancers, things like basal cell, squamous cell. Although melanoma is possible which is the more serious type of skin cancer.

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Blood cancers can also occur, things like acute myeloid leukemia and myelodysplastic syndrome. This is highest in patients with a prior history of fludarabine treatment. So some of you who have, have had this diagnosis for a long time may have received fludarabine and those of you with a newer diagnosis are likely not ever going to receive fludarabine but this...

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is, this is still a risk for everyone, these blood cancers.

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And then, lastly, a host of solid tumors. The most common ones are prostate cancer, colon cancer, breast cancer. But really any solid tumor is possible…

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for patients with CLL, as a second malignancy.

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So what can you do about this?

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So, regular screening per national guidelines and the caveat here is, it depends on your age and your risk factors, both your family history, your own health history. So there's not a cookie cutter solution here. This is something that you should be talking to your...

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primary care provider about.

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But in reality, everyone should be talking about and getting regular colon screening, whether it's Cologuard or colonoscopy, and then based on those results,..

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your GI provider will be telling you whether you should be having these done every three years, every 5 years, every 10 years.

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Prostate screening is important for the men, a a good prostate exam, PSA blood testing. And then for women, breast and GYN screening with mammograms and pap smears really just getting your good routine screening done.

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Because of that risk of…

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skin cancers. Skin care is definitely important, sunscreen, avoiding, you know, high times sun and sunburn.

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And then routine dermatology exams are also very important. I really like everyone with CLL to have a dermatologist and have regular dermatology exams because of that high frequency of…

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skin cancers in addition, for, for anyone who is smoking or using smokeless tobacco, there are many programs available, you know. Some are support groups. Some offer nicotine patches, some offer other medications. There are all options for you know, smoking and tobacco cessation, and then also regular dental care, because smoking,..

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a history of smoking or smokeless tobacco, use...

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Increases your risk of…

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oral cancers. So really making sure that you're seeing your dentist and having a good oral exam is important as well.

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So other things in the end, primary care visits. So keep those primary care visits.

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The frequency will be based on your health history, you might be going every three months. You might be going every month. You might be going every year but keep those appointments, whatever…

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schedule your primary care provider recommends. Keep the schedule.

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Seeing your oncologist…

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does not…

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take the place of seeing your primary care provider.

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When you see your oncologist, we are focused on your CLL. We are not keeping track of when your colonoscopies were, when your pap smear is due, when your next PSA is due. We're not keeping track of any of those things, so your primary care provider is very important, even if you are in, feel like you're in your oncology office all the time.

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We are not keeping up with your schedule for your routine…

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health maintenance.

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And then, of course, seeking out medical care with any persistent or worsening new symptoms.

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Don't ignore, don't ignore things, you know. Get things checked out if you're having new symptoms.

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So cardiovascular disease.

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In general,..

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there is a high rate of cardiovascular disease, and people with CLL...

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simply out of the gate, due to the fact that this is a disease of older people, and in this country, older people commonly have cardiovascular disease.

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So it's estimated that a third of patients have significant cardiovascular disease at the time of diagnosis and before the first CLL treatment. That's not a third of patients with cardiovascular disease, it's with significant cardiovascular disease.

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And then some treatments for CLL,..

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mainly our BTK inhibitors, do increase the risk of cardiovascular disease, specifically, high blood pressure or hypertension and abnormal heart rhythms.

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So, if you are on a BTK inhibitor or you are starting a BTK inhibitor, you may have a baseline EKG done…

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prior to starting this therapy. We do have second generation acalabrutinib and zanubrutinib that have lower cardiovascular risks. But all drugs in this family do have this risk.

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And then, if you do develop cardiovascular side effects, you may be referred to a cardio oncologist or definitely a cardiologist, depending on whether your practice has access to a cardio oncologist or not, but definitely seeing a cardiologist is going to be recommended.

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So how can you prevent these cardiovascular complications? And, and remember, these are, these are largely unrelated to CLL.

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Regular screenings. So, prevention with regular screenings with your primary care, all your specialists. If you have a cardiologist, endocrinologist, a vascular specialist, see all of your specialists. The oncologist is not the cardiologist. Your oncologist is not your endocrinologist.

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Please see all of your, your regular doctors.

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Physical activity is absolutely important here…

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to keeping your cardiovascular health as optimal as you can. A healthy diet,..

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weight control, also taking medications as prescribed.

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You know, you're, we tend in oncology to have people on a lot of medications, but you've got to take everything. All of the things that you came to your CLL diagnosis taking,...

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as well as all the additional things that we may be prescribing.

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For blood pressure control, home monitoring if that's, if someone's telling you to monitor at home, please be compliant with that…

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schedule. Whatever your primary care cardiologist is telling you to do with home monitoring, please do it. Reducing stress, managing anxiety. Those are very important for blood pressure control also, and then for glucose control, home monitoring. If you do have diabetes or pre-diabetes and then really following that diabetic diet if you do have…

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those glucose issues.

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Bone health is another issue for patients with…

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a history, with a diagnosis of chronic lymphocytic leukemia. There are higher rates of osteoporosis…

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and fragility fractures in people with CLL compared to the same age and gender of person in this country that does not have a diagnosis of CLL.

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And these fragility fractures, which are fractures that, that are...

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that, that require very little trauma.

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These fractures are seen even without osteoporosis and osteoporosis is low bone density where your bones are not strong.

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And this is due to enzymes and other substances that are secreted by CLL, that cause an increase in bone loss and a reduction in bone repair ability.

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This is also a function of age, and again, CLL tends to be..

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seen in older people. So between the CLL and age,..

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bone health is definitely an issue.

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When the CLL is treated, that can reduce some of the bone loss, because those enzymes and other substances being secreted by the CLL quiet down.

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But if your regimen includes steroids, that promotes bone loss, so sometimes it's a double-edged sword. But this is definitely something for everyone with a history of CLL to be aware of.

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So what can you do to promote or maintain your bone health?

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Optimizing vitamin D and calcium levels with your primary care is important. Do not just take supplements without discussing with your primary care. There are other medical conditions that can…

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make this not recommended and based on your kidney function, and lots of lots of different factors, you may or may not be recommended to...

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take supplements. So please talk to your primary care about this.

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Weight bearing exercise is another way to promote or maintain your bone health. And again, if you have any,..

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any like, any bone issues, any of,..

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you know, arthritis, anything that that may make weight bearing exercise for you; this is definitely something you should be talking to your primary care provider about, what are appropriate weight bearing exercises for you and that is going to look different for everyone.

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Bone density screening. So for females this is this is recommended somewhere around age 60 or 65. It may be recommended earlier, and also for men. If you've had steroid exposure, if you have other risk factors, other health issues that also…

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are problematic for bone health. So again, talking to your primary care, provider is critical here.

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If you have any abnormalities in your bone density, you should be referred to a bone density or a metabolic bone clinic quickly.

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It's not an emergency but you should be referred for specialized care.

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There are therapies that,..

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that slow down your body's reabsorption of bone that may be appropriate, and those bone density or metabolic bone clinic folks are really good at…

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working that up and making sure that you're getting the right therapies.

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And then there are times that physical occupational therapy exercise, physiology, referrals may be appropriate, especially if you have issues that weight bearing exercises may be...

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difficult for you. Some of those specialties may be able to help you there too. Some of those therapy options may be appropriate.

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So dental health. There is very limited research in dental health in patients with CLL, but we know…

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that folks with CLL have higher rates of dental disease and higher rates of dental treatment needs.

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The highest incidence is in people who have been exposed to chemotherapy, and you know, those of us who work in oncology, we know that mouth dryness is very common…

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with chemotherapy. It decreases your saliva and saliva keeps your teeth clean. And so that's, that's definitely part of it. But again, limited research has been done here.

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Strategies to reduce that risk or regular dental care, are then just keeping your mouth clean, optimizing your dental and oral hygiene.

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So emotional and psychological health in patients with CLL. This is another very understudied aspect of patients with CLL.

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So all of you know, that this chronic, slow, growing…

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disease with minimal symptoms and lots of observation. Watch and wait, active surveillance,..

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it results in uncertainty.

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And it's commonly not what people anticipate after getting a cancer diagnosis. Most people get a cancer diagnosis and expect to start receiving some sort of treatment and that's not the appropriate thing for most patients with a CLL diagnosis. So, so this is definitely an, an issue.

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When we look at emotional quality of life survey,..

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surveys, they show reduced results in patients with CLL. And those results do not improve over time. So this is not an issue of…

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less emotional quality of life at the time of diagnosis, it persists throughout someone's diagnosis.

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It is very common for people to be very anxious around the time of their medical visits. And then again, there's really no difference, not only in emotional quality of life but when we look at depression, anxiety, and quality of life surveys, there's no difference...

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in these ratings in patients under active or those in active treatment. So again, these, these things persist, regardless of what phase of a CLL diagnosis someone is in.

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So what can you do to improve and or maintain your emotional and psychological health?

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So, screening at diagnosis for depression, for anxiety at regular intervals. At the time of a change of treatment status or treatment initiation.

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Early referrals to psychology or counseling, close involvement with primary care providers. Many of the…

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considerations for medications are, are reliant upon your other medications, your, your overall health, history.

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So you know, seeing your primary care provider, seeing a psychologist, a counselor, those are very important. Caregiver support is very important. Social work referrals are important.

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There are local cancer support services, support groups, there are peer support options for, for people with CLL diagnosis.

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So, there are also CLL Society resources and so.

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there are approximately 40 support groups run by the CLL Society.

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They're held virtually in the United States and Canada. The CLL Society has support groups specific to watch and wait, to veterans with CLL.

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And then support groups are really, they're a place of camaraderie, and there's a lot of knowledge that is shared among the members. So I would really encourage both those of you with a CLL diagnosis and those of you who are caregivers to consider these support groups.

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And there are also…

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additional. There's a one-on-one emotional and spiritual advocacy program. There's one-on-one with a board-certified chaplain.

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You can be a person of faith. You can be a person with without strong faith, but it really helps explore coping mechanisms, spiritualism, meaning finding,..

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making goals of care, conversations, you know, grief support, all sorts of good things.

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And then there's a peer support system which is a one-on-one with an individual impacted by CLL, and that peer support is really good at sharing their own experiences, helping you navigate…

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watch and wait, insurance. You know the right questions to ask making treatment decisions, side effect management. So these are really good...

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support programs that the CLL Society…

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offers, and I would encourage all of you to take advantage of those as well.

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And that that's my last content slide, and I am happy to take…

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questions from the audience.

00:39:15.000 --> 00:39:20.000
Alright, thank you, Amy. That was very clear and informative presentation about…

00:39:20.000 --> 00:39:22.000
CLL and our journey.

00:39:22.000 --> 00:39:32.000
And we will begin answering questions now from the audience, and we'll try to get as many as possible. But if we aren't able to get your question answered for any reason,..

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please email Ask the Expert email address after this event. And at the end I'll share that email address in our closing slide.

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And we'd also like to thank everyone who submitted questions in advance,..

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that really makes our job easier to know…

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what your concerns are and also allows us to dig a little bit deeper into some of the questions that get asked.

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So with that I'd like to begin…

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with the questions. And…

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so the question I have, I'm going to start from the very top. We so far have 36 questions in.

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But I'll actually ask the questions that were submitted ahead of time.

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So,..

00:40:18.000 --> 00:40:20.000
is low sodium…

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typical in CLL?

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Does it explain an increased frequency in...

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foot and leg cramps?

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So the answer to that is yes to both of them. So all hematologic malignancy patients have a…

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the incidence, a higher incidence of hyponatremia or low sodium.

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This can be due to the drug, the medications that you're taking, the cancer medications, your regular medications. You know, if your lipids, your cholesterol, your glucoses, if those are not normal, there are so many things that, that interact, that impact…

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sodium, kidney disease, liver disease, infections. There's a huge list of things that impact sodium. But even in people who do not have any of those, if you have a hematological malignancy, you have a higher incidence of hyponatremia. This is really not well understood.

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The person who asked this question said that they…

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eat salty foods for those cramps, and, yes, eating salty foods if that helps your cramps. I also recommend that…

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people stay well hydrated.

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You know, eating those salty foods and then making sure that your potassium and magnesium are also normal, because those can contribute to those cramps as well. So just salty foods, good hydration and making sure that your potassium and magnesium are in normal ranges are, are what I recommend that folks do. We used to be able to give quinine for…

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cramps and the FDA took that off the market. The only way you can get quinine is with tonic water, so I tell folks get some diet tonic water too, if they like tonic water. That's a good way to get some hydration in and that helps those cramps as well.

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Okay? The next question has to do with weight gain and specifically ask about…

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acalabrutinib. But I'd like to broaden that question to all BTK inhibitors since…

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they operate, a lot of them operate the same way, so...

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Is weight gain something that's common within BTK inhibitors?

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Yes, weight gain is a side effect of all BTK inhibitors and the...

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the best working...

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theory about why that happens is…

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when CLL is active,..

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you have wasting muscle and fat wasting because the CLL is taking so much energy, and is…

00:42:57.000 --> 00:43:04.000
secreting enzymes that like literally, you're losing your, your body mass.

00:43:04.000 --> 00:43:12.000
And then when that gets turned around and the CLL gets treated that stops so that's really part of it.

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There is not, some patients very rarely can people actually have some fluid. It's usually not fluid…

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accumulation. It's, it's literally just weight gain. And, and you know the best, the best theory is that that, you know, your body…

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you know, your body is essentially eating itself, you know, using your body stores as energy goes away when you get treated. And so that you know, really this person who asked this question said, I eat a healthy diet. Definitely exercising is important there too. So really, just watching diet and exercise with that is a very, very common issue with BTK inhibitors.

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Okay, next question has to do with…

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fatigue and just general energy levels. But…

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we know that at the onset of…

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beginning before treatment, sometimes fatigue plays a role…

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in determining whether or not a patient is going to need treatment or not.

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So the question is, if I begin treatment are my energy levels going to increase and is my fatigue going to lessen?

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Yes, so if your fatigue is truly from your CLL, you should feel better.

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The slippery slope there is that, you know, most people with the CLL diagnosis are older and have, have a host of, of medical problems many of which can cause fatigue. Sometimes it's really hard to flesh out but if it's really, truly from the CLL, you should feel better. The other thing that I always do when people have profound fatigue is making sure that you know your,..

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you know, your thyroid level is normal. Your B12. You're doing some vitamin and electrolyte levels to make sure that there's not a deficiency somewhere also contributing to that is important, but also your other health problems. But yes, if it's really from the CLL, you should feel better. Exercise also helps fatigue. It's sort of counterintuitive, but the more active you can stay, you can sometimes overcome…

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that fatigue or, or have it be minimal, minimized…

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with exercise.

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Okay. You touched on this a little bit on your slides about the bone health.

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And so the question is specifically,..

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does bone health treatments

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lower your immunity?

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So this, this person actually put a reference in there. And I looked at that reference and they're in the lab.

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It does look it, when you put blood from people with CLL together with these bone health drugs, these osteoporosis therapies, it does appear to make the CLL a little more active.

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That's in the lab, and we all know, those of you who've ever looked at a study, you know that there are a lot of things that happen in the lab that don't equate to what happens in reality. So this group, it was an Italian group,..

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they recommended that in future clinical trials, that, that be an endpoint that that be watched and started to collect that in clinical trials. You know where you're really going through the list of everyone's medications.

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And so there's, they're, they're not suggesting that people with osteoporosis do not get those therapies. They're suggesting that we should, as scientists, our thought leaders should really be looking into this in real people, as we're doing trials.

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Okay.

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I'm going to go now to the questions that were submitted today…

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and…

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I don't know if you know if there's an answer for this one but...

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what is the average age…

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that CLL patients…

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require treatment? We know the average age…

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of diagnosis.

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Oh, yes, so right that you know what that depends on your prognostic factors and how fast you're, you know, how fast your disease, you know, progresses after you get that diagnosis. You know, we know that...

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I, I mean, I don't, I've never seen data. So that's a great question. I don't have an answer.

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Yeah. I mean, it's in our support groups, it's all over the map.

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Yeah, yeah.

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Age wise of when and you're exactly right, it, it really has to do with…

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Yeah.

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their CLL specifically, that's why…

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CLL is such a heterogeneous disease that…

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Yeah.

00:47:53.000 --> 00:47:54.000
you know, you can't really necessarily predict the future when you might start treatment, so…

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Yes, yes, there's no cookie cutter.

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No, no.

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So this one says, does the CAPTIVATE data at ASCO...

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make retreatment more compelling..

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and is there any specific patient profile that retreatment is more suited?

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Hmm.

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And is there an increased interest in...

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BTK, BCL2 combinations because of retreatment potential?

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So that is…

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that's the million dollar question, right? And so that is the, that is the…

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we're.

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Okay. So we know what happens when we give these drugs sequentially, right, that you get a BTK inhibitor and then you get a venetoclax based therapy or the other way around. We know what happens.

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We don't know what happens when we put those drugs together…

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and how people are going to respond down the line.

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In my clinical practice, we tend to repeat the venetoclax. I know that's not,. that's not standard. There's no cookie cutter answer. Again, that is a great question.

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And I think time will tell. So in these trials that combine a BTK inhibitor and venetoclax, they are keeping track of who's treated with what next, and how they do on that next therapy.

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And you know the good news is…

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people are doing really well on these regimens and stay in remission for a very long period of time. So, it is going to take a long time for us to figure out…

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what the best strategy is moving forward and it may be different for people with a 17p deletion than it is for people without a 17p deletion, or what, what your IGHV status is we don't know. I always say studying CLL is not for people who are impatient because it takes so long to figure out.

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Right.

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You know the right course after, after a study like this. But it is a great question. You're ahead of your time.

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Here's one from an untreated patient, this my white count has jumped from 29 to 49 in less than a month…

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and I'm having quite a bit of bruising.

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Is the bruising a bad sign? I would, I would go back to is the increase in the…

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WBC a bad sign, but…

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but put both of those together, maybe.

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So the bruising, I would, I would want to know what your platelet count was. So there's really no magic white blood cell count for treating. CLL. The issue is that as your bone marrow gets so packed with CLL cells, you start losing your capacity to make other normal cells. Normal cells, really, neutrophils are the big ones. People can become neutropenic, you can get anemia.

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Your hemoglobin and hematocrit can drop, your platelets can also get low, so that bruising, I would wonder what your platelet count is.

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The 49,000 white blood cell count is not an automatic trigger, you know, going from 29 to 49 is not an automatic trigger to do anything. But if, if your other cell lines are dropping off that, that may be an issue, so you should definitely report that bruising and, and get some labs done, and get seen.

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And it's really the trend, more than one test as well.

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Yes, never get excited over one,..

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one value. We want to see a trend, infections, medications, other illnesses. There are so many things that can make your counts go crazy.

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Yeah.

00:51:42.000 --> 00:51:51.000
And then, you know, the next month you get them checked again, and they're back to what they usually are closer, you know, closer to where they usually have been, but any sort of illness,..

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new issues, new drugs, hospitalizations for anything, you know, you get a knee replacement, anything can set those counts off.

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Yeah.

00:52:01.000 --> 00:52:03.000

00:52:03.000 --> 00:52:05.000
Okay, this one, yeah,..

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kind of opens up a door…

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really for the question of.

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continuous therapy versus,..

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you know, a, a fixed time therapy, and..

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but the question is around what is the primary reasons for using a venetoclax based regimen...

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and are there any patient profiles that seem to fit that...

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more than a BTKi?

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So,..

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okay, that, that is a great question and…

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okay, so when I talk to patients about these regimens, it's really about what fits into your lifestyle for most patients, whether you want just to take a pill as long as it's working versus the venetoclax, where for the first couple of months there are really a lot of visits, there are infusions, but you're done in a year.

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Okay, so for the average patient, it's really about what fits into your life.

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Aside from that,..

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patients with a 17p deletion or unmutated IGHV status...

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tend to do, have better responses to a BTK inhibitor than venetoclax with an anti-CD20, okay.

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But, today, if you started a BTK inhibitor, you have those prognostic factors and you started a BTK inhibitor and you were progressing and needed treatment, you would get a venetoclax based regimen. So...

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to me, it's more about…

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what fits your lifestyle...

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and what regimen you're going to be adhering to...

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more than anything else, because really, at some point,...

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if, if people…

00:53:54.000 --> 00:54:06.000
get, you know, if you get treated twice, if you're diagnosed today, you get treated twice, you're going to get a BTK inhibitor.

00:54:06.000 --> 00:54:07.000

Yeah.

00:54:07.000 --> 00:54:16.000
You know that these are just the best drugs that we have, even though those folks with 17p deletions are unmutated IGHV status do tend to respond better to BTK inhibitors.

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Right, right.

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Here's one that actually comes up in our, in our support group sometimes. People are doing well on, let's say ibrutinib...

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and…

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now they realize their doctor is no longer prescribing ibrutinib as a first-line treatment, and so they ask the question, well, should I switch to acalabrutinib or zanubrutinib…

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because they have less...

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adverse events?

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And I know my medical team said that, you know, if you're doing well on ibrutinib,..

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they don't see a reason to really change. It's when you have issues that they can't manage,..

00:54:58.000 --> 00:55:03.000
then they would look at possibly changing. But in your practice do you,..

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would you look at changing a patient that's on ibrutinib to something else if there were really no adverse events?

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Yeah, no, no, we're not. We're not switching if you're tolerating it. They're all good drugs. They all work very well and if you're tolerating it, there's no reason to switch.

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There were also, there was an update to the NCCN guidelines this year that also,..

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it was based on data about dose reductions that you should do dose reductions before switching agents as well. And there's a lot of data showing for ibrutinib, acalabrutinib, those two especially because they are older ones that dose reductions do not impact the efficacy.

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So, you know, if you're having side effects, even then dose reduce is what the NCCN guidelines say before switching agents. So yes, just if you're tolerating it, just feel comfortable that that is the right thing.

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Is, is, I've also read that…

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for somebody that has been on ibrutinib for let's say for 2 or 3 years,..

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the dose reduction is with,..

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is, has less risk at that point, if they have stable disease, correct?

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Yes, yes. Then doing it early, right? Yes, of course. Yes. Yup.

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Okay.

00:56:24.000 --> 00:56:25.000
Definitely thanks for saying that Terry.

00:56:25.000 --> 00:56:29.000
Okay.

00:56:29.000 --> 00:56:32.000
Let's see, this one's getting a,..

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a little out there but in high risk patients thoughts on using…

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bispecifics as a consolidation therapy…

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if MRD on completion of a combo therapy of BTK plus BCL2?

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So,..

00:56:55.000 --> 00:56:56.000
correct.

00:56:56.000 --> 00:56:57.000
That that would have to be done on a trial. That is not FDA approved. And I'm actually, I don't…

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I mean, there are bispecific trials going on in CLL. I don't know if the criteria, or exactly what you're saying, but, you know, there are bispecific trials and I would encourage, you know, everybody to look at those.

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Yeah.

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Right.

00:57:16.000 --> 00:57:19.000
Because they have been really promising in in many other diseases, and, and our FDA approved for many other diseases.

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Right. You kind of answered this before in the fatigue question it says...

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why so long after treatment do I still feel fatigued?

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My treatment was in 2011,..

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it was Stage 4. I assume they're doing...

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well now, but why do they still feel fatigued?

00:57:38.000 --> 00:57:58.000
Yeah, I would, I would really ask what your other health issues were, what your, what your other medications are.

00:57:58.000 --> 00:57:59.000
Yeah.

00:57:59.000 --> 00:58:03.000
You know. The other thing is, you know, 2011 was a long time ago now. I'm not sure any of us feel like we did in 2011, you know. And that's, I mean, that's another thing, you know, that's 13 years ago.

00:58:03.000 --> 00:58:11.000
But really looking at your other health conditions, your medications, you know. What are your blood counts doing? You have anemia. Those are the things I would be asking.

00:58:11.000 --> 00:58:16.000
Not, not everything is CLL.

00:58:16.000 --> 00:58:17.000
Right, right.

00:58:17.000 --> 00:58:18.000
We tell patients…

00:58:18.000 --> 00:58:19.000
Right.

00:58:19.000 --> 00:58:21.000
Do you recommend IV vitamin treatments…

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for general overall health for CLL patients?

00:58:24.000 --> 00:58:33.000
So, I am not aware of any studies that have found that to be impactful for the disease itself.

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You know there are lots of clinics out there doing vitamin and you know different infusions. I don't object to people doing that, but I don't, that's not something I, I steer people toward. I think if you take a multivitamin and your vitamin and mineral levels are good and you're eating a good balanced diet, you know, when we get a lot of those extra vitamins and minerals, we pee them out, you know,..

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your kidneys just send them, you know, out in your urine.

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So I I'm not sure,..

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there's enough data right now to, I know there's not enough data to recommend that.

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Right,..

00:59:12.000 --> 00:59:14.000
I think…

00:59:14.000 --> 00:59:17.000
this was misspelled, but it says, is...

00:59:17.000 --> 00:59:20.000
CIDP…

00:59:20.000 --> 00:59:26.000
a complication of CLL?

00:59:26.000 --> 00:59:27.000
Yeah.

00:59:27.000 --> 00:59:31.000
Common immune deficiency, common. CIDP, I'm blanking CIDP.

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Common immune deficiency?

00:59:36.000 --> 00:59:42.000
Hang on a second.

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CIDP.

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I was wondering if it was COPD?

00:59:46.000 --> 00:59:50.000
CIDP.

00:59:50.000 --> 00:59:53.000
Yeah. Common immune deficiency.

00:59:53.000 --> 01:00:08.000
Oh, chronic inflammatory demyelinating polyradiculoneuropathy!! Oh, I knew that, that I knew that wasn't right. What was coming to my head, polyradiculoneuropathy. That is, that is an autoimmune disorder.

01:00:08.000 --> 01:00:11.000
And we know that…

01:00:11.000 --> 01:00:23.000
people with a diagnosis of CLL have a higher incidence of autoimmune disorders. But it doesn't go the other way around. If you have an autoimmune disorder that does not…

01:00:23.000 --> 01:00:29.000
predispose you to CLL. So, so all...

01:00:29.000 --> 01:00:36.000
autoimmune disorders have a higher incidence in people with a diagnosis of CLL…

01:00:36.000 --> 01:00:45.000
Yeah, so that's, that's definitely on the list of things that are possible. I did talk about the hemolytic anemia and the ITP.

01:00:45.000 --> 01:00:53.000
Those are really the most common ones. But you know, I've got lots of patients with all sorts of autoimmune disorders, yes.

01:00:53.000 --> 01:00:55.000
Okay.

01:00:55.000 --> 01:00:57.000

We talked a little bit about IVIG...

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and the question here is…

01:01:01.000 --> 01:01:08.000
how, how long after IVIG did the levels increase or peak? I guess,..

01:01:08.000 --> 01:01:12.000
yeah, maybe to just expand that and say, what's the half-life of…

01:01:12.000 --> 01:01:14.000
IVIG, and how often do you get it?

01:01:14.000 --> 01:01:18.000
Right. So we know that if you're getting…

01:01:18.000 --> 01:01:25.000
monthly IVIG infusions, it spikes up, and by the time you get your next infusion it's gone.

01:01:25.000 --> 01:01:32.000
We have actually stopped giving IV IgG. We give the subcutaneous..

01:01:32.000 --> 01:01:35.000
products. There are a couple of them...

01:01:35.000 --> 01:01:39.000
that are self administered at home…

01:01:39.000 --> 01:01:59.000
and those flatten out the curve so you don't have all those peaks and valleys when you do subcutaneous. So we, we have stopped doing intravenous immunoglobulin because of that. Our immunology team feels very strongly that the subcutaneous route is, is the way to go to, to not have those…

01:01:59.000 --> 01:02:03.000
periods where your IgG is not rock bottom again.

01:02:03.000 --> 01:02:07.000
Right, and it saves you a trip to the infusion center.

01:02:14.000 --> 01:02:15.000
Yeah, yeah.

01:02:15.000 --> 01:02:25.000
Yes, yes, I mean no one, no one really likes self injecting, but they really love not being in the infusion chair and, and getting IVs put in and all of that. It's really much easier, eventually people realize that this is really the, a much more convenient way to do it. Yeah.

01:02:25.000 --> 01:02:31.000
Right. So, following up on IVIG, should vaccines be timed...

01:02:31.000 --> 01:02:33.000
to follow IVIG infusions?

01:02:33.000 --> 01:02:44.000
So if you are on IVIG, you do not, you do not, there are certain that you, you that you should get your flu shot.

01:02:44.000 --> 01:02:53.000
You, if you're getting IVIG, you are not going to respond to a COVID vaccination but…

01:02:53.000 --> 01:02:57.000
you're getting COVID antibodies in your IgG product.

01:02:57.000 --> 01:03:04.000
You should be talking to your healthcare team about vaccinations if you're getting IVIG.

01:03:04.000 --> 01:03:14.000
For sure, if you're on treatment, if you've had treatment in the last six months, it needs to be, your plan it needs to be customized.

01:03:14.000 --> 01:03:25.000
But in general, flu shots are, are recommended. Sort of blanket COVID. vaccinations may or may not be appropriate if you're on IgG.

01:03:25.000 --> 01:03:34.000
Our team, tell, our immunology team tells people don't get the RSV vaccine but that's just everybody's going to have a unique situation.

01:03:34.000 --> 01:03:37.000
Yeah. Ask your medical team.

01:03:38.000 --> 01:03:52.000

Ask your medical team, but if you're not getting treatment, you're not getting IgG, which is going to be most of the people on this, on this webinar, if you're not being treated, you haven't been treated in the last six months, you're not on IgG, you should get every vaccination that you're eligible to receive.

01:03:52.000 --> 01:03:53.000
Correct. Yeah.

01:03:53.000 --> 01:03:54.000
Yeah.

01:03:54.000 --> 01:04:02.000
Okay, one more. IVIG seems to be a hot topic today. I was given prednisone and Benadryl but developed an entire body rash…

01:04:02.000 --> 01:04:07.000
after my second IVIG infusion. My dermatologist said it was the prednisone…

01:04:07.000 --> 01:04:09.000
with a low immune system that cause..

01:04:09.000 --> 01:04:12.000
guttate psoriasis.

01:04:12.000 --> 01:04:16.000
Is there something else I could do to replace…

01:04:16.000 --> 01:04:21.000
IVIG infusions? Let, let me just say I've been taking IVIG for a number of years…

01:04:21.000 --> 01:04:24.000
and all of a sudden, during one of my infusions, I develop…

01:04:24.000 --> 01:04:30.000
hives and I went back and checked, and they had changed brands…

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of IVIG on me.

01:04:32.000 --> 01:04:36.000
And it was the only time in all those years that they had used a different brand.

01:04:36.000 --> 01:04:42.000

And once they went back to the old brand, I never had a reaction so…

01:04:42.000 --> 01:04:44.000
it could be the branding.

01:04:44.000 --> 01:04:47.000
But then I'll let you answer the question in terms of a replacement for IVIG.

01:04:47.000 --> 01:04:52.000
Right, well, the prednisone, if, if the…

01:04:52.000 --> 01:05:05.000
if the, your dermatologist really thinks that the reaction was from the prednisone, that prednisone is really the most critical for that first dose and it, you may really not need the prednisone moving forward if that was the problem.

01:05:05.000 --> 01:05:07.000
Right, right.

01:05:07.000 --> 01:05:11.000
Okay.

01:05:11.000 --> 01:05:14.000
Okay. Prophylactic shots for COVID, for,..

01:05:14.000 --> 01:05:16.000
you know,..

01:05:16.000 --> 01:05:24.000
we had, we have Pemgarda now, which is an infusion, but it is not an IgG infusion, it is an…

01:05:24.000 --> 01:05:26.000
infusion where you're,..

01:05:26.000 --> 01:05:31.000
you go in, and you're monitored for an hour or two afterwards giving you…

01:05:31.000 --> 01:05:35.000
some prophylactic protection from COVID…

01:05:35.000 --> 01:05:38.000
and…

01:05:38.000 --> 01:05:42.000
is this something that you see common in your…

01:05:42.000 --> 01:05:50.000
practice?

01:05:50.000 --> 01:05:51.000
Correct.

01:05:51.000 --> 01:05:52.000
So we're not giving a ton of Pemgarda. So this replaced Evusheld, for those of you who, who had received Evusheld….

01:05:52.000 --> 01:05:55.000
And so when, when…

01:05:55.000 --> 01:06:01.000
when folks are taught, when we talk, to have these discussions with patients,..

01:06:01.000 --> 01:06:19.000
I'm always checking their antibody levels first or their spike proteins to see if you have immunity. Right? So if you have immunity to COVID you, really, you didn't need Evusheld, back in the day when we were giving Evusheld and you really don't need Pemgarda if you have immunity.

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If you don't have immunity, then yes, that is in my practice, then that is, that is reasonable. What we find is that…

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people have been vaccinated over and over and over again, and even people whose immune systems we know are not working well at all, do have low level…

01:06:38.000 --> 01:06:40.000
antibodies.

01:06:40.000 --> 01:06:56.000
And so the, the real goal here is that if you have antibodies and you've been exposed to COVID and your immune system knows that you've seen COVID before, you can mount some response if you develop COVID.

01:06:56.000 --> 01:07:11.000

And so that prevents, you know, hospitalizations, and certainly is why, you know, our mortality rate from COVID has been slashed, and that really does apply to the CLL population as well, if you have immunity.

01:07:11.000 --> 01:07:13.000
You. You're good!

01:07:13.000 --> 01:07:20.000
If you don't, then Evusheld was appropriate and Pemgarda is appropriate.

01:07:20.000 --> 01:07:25.000
Okay, here's one. Is there a relationship between IgG and neutrophils?

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There is not because IgG…

01:07:30.000 --> 01:07:34.000
is the end product, of product of lymphocytes.

01:07:34.000 --> 01:07:36.000
So that's a lymphatic…

01:07:36.000 --> 01:07:42.000
family cell and neutrophils are more myeloid.

01:07:42.000 --> 01:07:43.000
Okay.

01:07:43.000 --> 01:07:45.000
So yeah, they're, they're totally different families.

01:07:45.000 --> 01:07:47.000
Okay.

01:07:47.000 --> 01:07:51.000
You answered some questions about autoimmune complications,

01:07:51.000 --> 01:07:53.000
ITP and...

01:07:53.000 --> 01:08:01.000
AIHA today. So there's, ah, I think that question has been answered.

01:08:01.000 --> 01:08:03.000
Do all white blood cells…

01:08:03.000 --> 01:08:08.000
not work properly with CLL or are there a certain percentage that don't work…

01:08:08.000 --> 01:08:11.000
properly depending on stage?

01:08:11.000 --> 01:08:13.000
It's, it's the lymphocytes that don't work,..

01:08:13.000 --> 01:08:27.000
don't work well. They appear mature under the microscope. But functionally, they're very immature. Your neutrophils, your other, your other types of white blood cells, they're, they're fine.

01:08:27.000 --> 01:08:28.000
Yes, that's a good question.

01:08:28.000 --> 01:08:31.000
Okay.

01:08:31.000 --> 01:08:35.000
This is a COVID question. Should I be concerned about visiting family...

01:08:35.000 --> 01:08:37.000
that have not taken the COVID shot?

01:08:37.000 --> 01:08:41.000
I would ask you if you had antibodies.

01:08:41.000 --> 01:08:45.000
Right. If you have antibodies and you can protect yourself…

01:08:45.000 --> 01:08:51.000
That, that then you, you have to just do what you feel is right.

01:08:51.000 --> 01:08:53.000
I, I really encourage…

01:08:53.000 --> 01:09:02.000

people to really mobilize their family members, and, you know, encourage them so that they don't give it to them. But if you have immunity,..

01:09:02.000 --> 01:09:05.000
you're, you're probably okay.

01:09:05.000 --> 01:09:09.000
Okay.

01:09:09.000 --> 01:09:12.000
Talking about fatigue and sleepiness again.

01:09:12.000 --> 01:09:17.000
Can a stimulant like Adderall be prescribed to offset this?

01:09:17.000 --> 01:09:25.000
That, that's really a last resort. Yes, I have had, I have had, I have had people on...

01:09:25.000 --> 01:09:28.000
Ritalin, Adderall, things like that.

01:09:28.000 --> 01:09:31.000
They have very variable results.

01:09:31.000 --> 01:09:35.000
I would be looking for every single…

01:09:35.000 --> 01:09:45.000
cause of fatigue before I, I started those if you were so, you know somebody I was seeing.

01:09:45.000 --> 01:09:50.000
I develop urticaria last year with no environmental triggers.

01:09:50.000 --> 01:09:55.000
Could it be an autoimmune response from the CLL?

01:09:55.000 --> 01:10:02.000
, that is, that's a hard question to answer. We do know that…

01:10:02.000 --> 01:10:08.000
people with a diagnosis of CLL have responses to…

01:10:08.000 --> 01:10:18.000
like bug bites to you know, things that do cause skin eruptions. We know that their skin eruptions tend to be pretty significant.

01:10:18.000 --> 01:10:27.000
So they, it could have been I'm, I'm saying it could have been. I, I would need a whole lot more detail. But yes, that is possible.

01:10:27.000 --> 01:10:29.000
Okay.

01:10:29.000 --> 01:10:36.000
We get this question a lot in our support groups about when you're feeling ill,..

01:10:36.000 --> 01:10:38.000
when should you make that call to the doctor's office to say...

01:10:38.000 --> 01:10:43.000
you know, I would think I'm having something going on here, and…

01:10:43.000 --> 01:10:47.000
you know, can I come in and see you? So? What are the, what are the triggers…

01:10:47.000 --> 01:10:51.000
that would generate the call to your doctor?

01:10:51.000 --> 01:11:16.000
Well, they're, they're really, they're really variable. So in our, we got a, I'll use the example, we got one of our pre-questions with somebody, saying that they've been very short of breath for the last three weeks with any activity, they're very short of breath immediately you should be reporting that. You know, if you have a cold, and it hasn't been a week, you're not blowing green or brown...

01:11:16.000 --> 01:11:25.000
stuff out or coughing green or brown stuff out. You're not having respiratory difficulty. Riding minor things out does make sense.

01:11:25.000 --> 01:11:47.000
But if you have, especially if you're on treatment, if you have, if you're having new symptoms that you can't control with the drugs that you have at home. Don't wait a week. Call. And it may be that they say, okay, well, do this and wait two or three days and then update us again. Especially if you have a portal,…

01:11:47.000 --> 01:12:12.000
shooting messages through those portals and just saying, hey, this is going on. I'm really not sure this is an issue. But you know it has me concerned. That, that's definitely a good option. You can always pick up the phone and call. But if you're really just having something mild that you're worried about, you know, shoot a message to the portal. If, if there's something that you are really concerned about, pick up the phone…

01:12:12.000 --> 01:12:18.000
And definitely call. You know, the, the breadth of things that could happen…

01:12:18.000 --> 01:12:26.000
are, it's too extensive to even try to cover all of the things that you should call for. Yeah.

01:12:26.000 --> 01:12:32.000
This one has to do with platelets and baby aspirin.

01:12:32.000 --> 01:12:35.000
Is a platelet level of 140…

01:12:35.000 --> 01:12:38.000
concerning if I'm taking a daily baby aspirin?

01:12:38.000 --> 01:12:49.000
No, no, not at all, no, not at all. No, your platelet count has to get well below 50 for your, for your baby aspirin to cause issues. Yeah, that's a good question.

01:12:49.000 --> 01:12:51.000
Okay.

01:12:51.000 --> 01:12:55.000
I think this is a cardiovascular…

01:12:55.000 --> 01:13:01.000
physician question, but there was a study done in 2023, the role of cholesterol and...

01:13:01.000 --> 01:13:04.000
chronic lymphatic leukemia.

01:13:04.000 --> 01:13:09.000
And is there anything I can do to…

01:13:09.000 --> 01:13:12.000
lower my LDL?

01:13:12.000 --> 01:13:14.000
So.

01:13:14.000 --> 01:13:17.000
Diet, exercise, medications. Those were, those are the…

01:13:17.000 --> 01:13:19.000
Yeah.

01:13:19.000 --> 01:13:21.000
Yeah, those are the.

01:13:21.000 --> 01:13:26.000
You know? Again, just keeping…

01:13:26.000 --> 01:13:35.000
Everything that you can under control, well-controlled I,s is really important in folks with a diagnosis of CLL.

01:13:35.000 --> 01:13:38.000
Okay.

01:13:38.000 --> 01:13:41.000
We just had this question last this month in our…

01:13:41.000 --> 01:13:44.000
in our support group meeting about dental health. Someone was having an...

01:13:44.000 --> 01:13:53.000
implant done. Somebody else was having a root canal and the question came about out about doing prophylactic antibiotics before a major…

01:13:53.000 --> 01:13:55.000
Hmm.

01:13:55.000 --> 01:14:01.000
dental procedure, not necessarily a cleaning, but something like a root canal, or you know…

01:14:01.000 --> 01:14:04.000
something where they have to do an implant with a bone so…

01:14:04.000 --> 01:14:07.000
is there a recommendation for…

01:14:07.000 --> 01:14:10.000
antibiotics before those types of major procedures?

01:14:10.000 --> 01:14:35.000
So as someone who's had bone grafting done, I got antibiotics. I do not have CLL. So if you're having a major procedure, you are going to get antibiotics, and you should get antibiotics. The real question is, what's your platelet count what's your neutrophil count, you know, just making sure that that there aren't going to be additional issues. But for those big procedures there, the dentist is prescribing antibiotics that you should absolutely take them.

01:14:35.000 --> 01:14:37.000
Okay.

01:14:37.000 --> 01:14:41.000
Here's, here's an interesting one, because you hear…

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this all the time, even IVIG, they have labels on it that say...

01:14:46.000 --> 01:14:49.000
chemotherapy. But it says…

01:14:49.000 --> 01:14:53.000
they keep hearing about chemotherapy, and how bad it is.

01:14:53.000 --> 01:14:57.000
But is obinutuzumab + venetoclax treatment considered chemotherapy treatment?

01:15:00.000 --> 01:15:03.000
It's not. So, venetoclax is a…

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BCL2 inhibitor. It's a targeted oral drug, and obinutuzumab is a monoclonal antibody.

01:15:11.000 --> 01:15:28.000
Chemotherapy, is typically what's, what patients with CLL could potentially get. I actually can't remember the last time I had a patient with CLL get chemotherapy, but things like bendamustine, fludarabine, cyclophosphamide,,,.

01:15:28.000 --> 01:15:38.000
these are probably drugs that most of you have not heard of, because we're just not using them. We have drugs that are more effective and, and significantly less toxic.

01:15:38.000 --> 01:15:39.000
Yeah, yeah.

01:15:39.000 --> 01:15:42.000
But everything is called chemo.

01:15:42.000 --> 01:15:46.000
Right and like, when you and when you go to an infusion center,..

01:15:46.000 --> 01:15:53.000
they like the way they get scheduled, it looks like you're getting chemo. It's, it's, it's sort of…

01:15:53.000 --> 01:15:59.000
it's, it's a real misnomer. But yes, you're, you're probably not getting chemotherapy.

01:15:59.000 --> 01:16:05.000
Right, right.

01:16:05.000 --> 01:16:07.000
This person is having trouble…

01:16:07.000 --> 01:16:10.000
getting routine dermatology screenings because,..

01:16:10.000 --> 01:16:13.000
they say they won't make an appointment unless you have an issue.

01:16:13.000 --> 01:16:16.000
I know for myself,..

01:16:16.000 --> 01:16:20.000
I'm seen every six months by my dermatology team.

01:16:20.000 --> 01:16:22.000
And,..

01:16:22.000 --> 01:16:25.000
and most of the people in our group...

01:16:25.000 --> 01:16:30.000
have regularly scheduled appointments with their dermatologists. Now this person is in Canada...

01:16:30.000 --> 01:16:33.000
so maybe their way of…

01:16:33.000 --> 01:16:36.000
dealing with dermatology is different but…

01:16:36.000 --> 01:16:40.000
I think it's mandatory for clients…

01:16:40.000 --> 01:16:43.000
to have skin checks because of the issues coming up with,..

01:16:43.000 --> 01:16:48.000
you know, dermatology cancer. So I don't know what we…

01:16:48.000 --> 01:16:50.000
can offer with this person.

01:16:50.000 --> 01:16:57.000
Yeah, yeah. I would, I would ask if your dermatologist is aware that you have this diagnosis because...

01:16:57.000 --> 01:17:16.000
skin cancers are the most common second malignancy that people with a diagnosis of CLL develop. So, I like everyone to have a dermatologist and see them at least once a year, you know, depending on what they're seeing, you may be every six months you may be more frequent than that.

01:17:16.000 --> 01:17:17.000
Yeah.

01:17:17.000 --> 01:17:20.000
Yeah, they ask, are there specific guidelines? And I would just do a search on,..

01:17:20.000 --> 01:17:24.000
you know,..

01:17:24.000 --> 01:17:25.000

Yeah, yeah.

01:17:25.000 --> 01:17:27.000
Search dermatology, cancer and CLL and I'm sure you're going to get a ton of articles about that…

01:17:27.000 --> 01:17:28.000
Yeah, yeah.

01:17:28.000 --> 01:17:32.000
specifying that the fact that we, as CLL patients,...

01:17:32.000 --> 01:17:40.000
you know, are more likely to have skin issues than the normal population. So just take that with you and say, hey, this is why I'm concerned.

01:17:40.000 --> 01:17:44.000
And this is why I want to be checked. I mean, that would be…

01:17:44.000 --> 01:17:56.000
my recommendation.

01:17:56.000 --> 01:18:05.000
Correct.

01:18:05.000 --> 01:18:06.000
Yeah, yeah.

01:18:06.000 --> 01:18:08.000
Yes, I agree. But part of, part of it in the United States is that if you don't go frequently and you have a problem you can't get in. It may be different in Canada, right? That you know, with socialized medicine it may be different. I would, I would recommend you talk to your dermatologist and just make sure they, they are aware of this increased risk of skin cancers in in people with a CLL diagnosis. Yeah.

01:18:08.000 --> 01:18:14.000
I like the, the start of this question. It's a silly question. Well, number one…

01:18:14.000 --> 01:18:18.000
believe me, no question is silly, but…

01:18:18.000 --> 01:18:24.000
It, I'm not sure everybody knows this. Can a CLL patient donate blood?

01:18:24.000 --> 01:18:27.000
No, you cannot.

01:18:27.000 --> 01:18:28.000
Right.

01:18:28.000 --> 01:18:31.000
And it's a, it's a great thought. But no, you can't donate blood.

01:18:31.000 --> 01:18:32.000
Right.

01:18:32.000 --> 01:18:35.000
Anybody with a, I mean, really anyone with a malignancy,...

01:18:35.000 --> 01:18:38.000
a recent malignancy or a blood cancer, there, they…

01:18:38.000 --> 01:18:40.000
that you would screen out.

01:18:40.000 --> 01:18:42.000
Yeah, right.

01:18:42.000 --> 01:18:49.000
Is there a frequency set-up now for RSV vaccinations?

01:18:49.000 --> 01:18:53.000
It's a today, it's a one, you know. It's, it's, it's just…

01:18:53.000 --> 01:18:54.000
one time.

01:18:54.000 --> 01:18:57.000
You get, you get one. Yeah, it's a one time…

01:18:58.000 --> 01:19:04.000
Yeah. And follow that up, is there a frequency schedule for COVID?

01:19:04.000 --> 01:19:10.000
Well, it seems like we're getting a new one every fall that's covering the new variants.

01:19:10.000 --> 01:19:23.000
I know that the, the new ones just came out like in the past week or so they've been available here in Maryland, but prior to that, pharmacies weren't even stocking the old one and they were waiting to get the new,..

01:19:23.000 --> 01:19:25.000
the new batch in.

01:19:25.000 --> 01:19:27.000
Yeah, yeah.

01:19:27.000 --> 01:19:32.000
Here's one. Should I get a pap smear? I'm 79 years old and have not had one in 10 years.

01:19:32.000 --> 01:19:36.000
You., you should talk to your GYN and your PCP.

01:19:36.000 --> 01:19:54.000
A lot of the pap smear frequency is based on your previous findings. Also, based on age, so definitely needs to be customized to you. But that's a great question. Ask the questions of the people who are taking care of you, and they'll, they'll guide you in the right direction.

01:19:54.000 --> 01:19:57.000
Right.

01:19:57.000 --> 01:20:02.000
This one comes up a lot, and people are confused about live vaccines…

01:20:02.000 --> 01:20:04.000
and we know that people can't get…

01:20:04.000 --> 01:20:08.000
live vaccines. But could you just give a couple of examples...

01:20:08.000 --> 01:20:11.000
of vaccines that are very common in the normal population that we could get.

01:20:11.000 --> 01:20:34.000
Yep. So when I think about vaccines and, and all the vaccines that you could potentially get, I think about people who've had bone marrow transplants or CAR-T, and they repeat their immunizations. The, and they get all their baby shots over again. They get

COVID vaccinations over again. They get every, they get their shingles, vaccines, they get everything.

01:20:34.000 --> 01:20:40.000
The only live one is MMR - measles, mumps, and rubella. That's the only…

01:20:40.000 --> 01:20:52.000
common live vaccine. Now, if you're traveling overseas, and your, your health department is recommending others like one off vaccinations, you, you need to ask about live vaccines.

01:20:52.000 --> 01:21:00.000
We do give patients, it's at the two year mark after the transplant or the CAR-T, that we give the live vaccine.

01:21:00.000 --> 01:21:22.000
And so, if you need a live vaccine, you should be asking your oncology team whether or not it's safe for you. When the shingles were live the first shingles that we had were live. We did not have patients get them and the ones who did often developed shingles. That's the, that's the issue.

01:21:22.000 --> 01:21:38.000
But since they're not live anymore, you know, we do recommend that everyone get those. But MMR is really in terms of the common ones that you think about when you know your kids or your nieces and nephews got their vaccinations. That's the one that's live. And we're not getting that repeated.

01:21:38.000 --> 01:21:39.000
Right, right.

01:21:39.000 --> 01:21:40.000
Yeah.

01:21:40.000 --> 01:21:47.000
Okay. Let's see.

01:21:47.000 --> 01:21:49.000
There's a lot of questions about…

01:21:49.000 --> 01:21:56.000
bone health here. There's one about can enzyme supplements be beneficial to counteract…

01:21:56.000 --> 01:21:59.000
bone loss. Here's another question…

01:21:59.000 --> 01:22:03.000
About…

01:22:03.000 --> 01:22:07.000
About, there are many different therapies, some are hormone...

01:22:07.000 --> 01:22:10.000
and some are not, which one...

01:22:10.000 --> 01:22:13.000
would be the best for CLL?

01:22:13.000 --> 01:22:16.000
So there! There is very little,…

01:22:16.000 --> 01:22:21.000
very little research on this, specifically in CLL.

01:22:21.000 --> 01:22:24.000
But I know that…

01:22:24.000 --> 01:22:26.000
the drugs that get recommended,..

01:22:26.000 --> 01:22:32.000
really it's driven by your what, your level of your bone loss.

01:22:32.000 --> 01:22:57.000
Do you? Do you have outright osteoporosis? Do you just have osteopenia? I would really recommend that if anyone is worried about their bone health, if you've had bone density studies done and they're not normal, you go to one of these bone health clinics. These folks who do this. This is their life's work doing this. And they're very helpful and they will steer you in the right direction.

01:22:57.000 --> 01:23:07.000
That is definitely something that is customized. And it's based on your kidney function and other medications that you're on. There are a whole host of factors that go into...

01:23:07.000 --> 01:23:12.000
which of these bone health drugs are recommended and why.

01:23:12.000 --> 01:23:17.000
Okay, we see this a lot, question a lot on the forums and…

01:23:17.000 --> 01:23:20.000
there's a wide variety of answers. But,..

01:23:20.000 --> 01:23:25.000
how bad is it to have a glass or two of wine a week with CLL?

01:23:25.000 --> 01:23:27.000
I am now in remission...

01:23:27.000 --> 01:23:30.000
and but my IgG is low.

01:23:30.000 --> 01:23:38.000
If so, what I tell people, if you're not getting treated and your liver function is normal and everything is normal.

01:23:38.000 --> 01:23:42.000
A drink or two a week is really not going,..

01:23:42.000 --> 01:23:51.000
not likely to hurt anything. I would recommend that you just ask all of your health providers that. I don't know what medications you're taking,..

01:23:51.000 --> 01:23:56.000
you know, what other health problems you have. but,, you know in general,..

01:23:56.000 --> 01:24:03.000
if you don't have a whole host of health problems are not on a lot of medications, you know,..

01:24:03.000 --> 01:24:08.000
very modest drinking is, is generally okay.

01:24:08.000 --> 01:24:14.000
I'm currently on zanubrutinib but I have to take prednisone steroids for one day. Is that a problem?

01:24:14.000 --> 01:24:17.000
You know, that's fine. Yep, absolutely fine!

01:24:17.000 --> 01:24:18.000
Yep.

01:24:18.000 --> 01:24:21.000
Okay.

01:24:21.000 --> 01:24:27.000
I'm confused about my IGVH status changing from mutated to unmutated...

01:24:27.000 --> 01:24:30.000
and I received conflicting information.

01:24:30.000 --> 01:24:35.000
Well, that is a rarity that those change so…

01:24:35.000 --> 01:24:38.000
it is, it's probably, it's,..

01:24:38.000 --> 01:24:46.000
it's almost more likely that one of those lab results was wrong than you actually...

01:24:46.000 --> 01:24:49.000
change, your, your status changed.

01:24:49.000 --> 01:24:55.000
Yeah, yeah.

01:24:55.000 --> 01:24:56.000
Right.

01:24:56.000 --> 01:25:01.000
Yeah. The incidence of a lab error is higher than truly having someone switch and, and I don't know if you had one done sort of in a.,,

01:25:01.000 --> 01:25:14.000
I, I don't know what this, whether it was the same lab that did them. Your oncology team should be able to tell you which one they think is, is the keeper and if there's any question you can always have it done again.

01:25:14.000 --> 01:25:15.000
Yeah.

01:25:15.000 --> 01:25:17.000
Right, right. Yeah, I've often heard that it was just…

01:25:17.000 --> 01:25:20.000
incorrectly read, depending on where you…

01:25:20.000 --> 01:25:21.000
Yes.

01:25:21.000 --> 01:25:27.000
test it. And if it's at a major medical center or educational center, more than likely it's going to be more accurate.

01:25:27.000 --> 01:25:28.000
Correct.

01:25:28.000 --> 01:25:29.000
So, yeah.

01:25:29.000 --> 01:25:32.000
Okay.

01:25:32.000 --> 01:25:39.000
Can taking a variety of medicines, including heart, gout, bladder, have an effect on a CLL patient…

01:25:39.000 --> 01:25:41.000
who, who is also on…

01:25:41.000 --> 01:25:44.000
they said chemo pills but Calquence.

01:25:44.000 --> 01:26:00.000
Yeah, yes. So, all of the oral therapies of ibrutinib, acalabrutinib, pirtobrutinib, venetoclax, all of the oral therapies have drug interactions. They, there can potentially be problematic drugs…

01:26:00.000 --> 01:26:04.000
and that is why it is so important that…

01:26:04.000 --> 01:26:15.000

every time you see your oncologist, really knowing what you're taking, not just prescription medications but over the counters, herbal, you know, supplements, vitamins, all of those things.

01:26:15.000 --> 01:26:27.000
Most oncology practices today have a pharmacist embedded in them, and there are people going through your medication list and making sure that you don't have any of these drug interactions. If you do,..

01:26:27.000 --> 01:26:34.000
the dose of the oral therapy that you're on for your CLL is often reduced…

01:26:34.000 --> 01:26:59.000
because it's, it's common for other medications to have the concentrations of the, the oral drug that you're getting for your CLL make them falsely high so you, maybe dose reductions that I would just recommend that you really include every single thing that you're putting in your mouth and not just your prescription medication, so that your team…

01:26:59.000 --> 01:27:07.000
can dose modify or be aware of those drug interactions.

01:27:07.000 --> 01:27:12.000
I don't know if this can be answered. But how long is the average time...

01:27:12.000 --> 01:27:16.000
that it takes for white blood cells to decrease

01:27:16.000 --> 01:27:19.000
using Brukinsa?

01:27:19.000 --> 01:27:21.000
I'm, let's just put all the BTKis in one category.

01:27:21.000 --> 01:27:26.000
Yes, yes. So that, that's a great question.

01:27:26.000 --> 01:27:34.000
One of the things that happens when people start a BTK inhibitor, what the part of the way they work is, they actually…

01:27:34.000 --> 01:27:37.000
shrink lymph nodes first…

01:27:37.000 --> 01:27:50.000
and the lymphocytes in your lymph nodes get pushed out into your bloodstream. And it's you, about 50 of people who start a BTK inhibitor will have a spike in their white, in their lymphocyte count…

01:27:50.000 --> 01:28:00.000
but you'll see your nodes shrinking. And then so, some people who have that spike there, they it may go down a little,..

01:28:00.000 --> 01:28:09.000
some people have an elevated lymphocyte count the entire time they're on the BTK inhibitor and it's not indicative of a lack of response.

01:28:09.000 --> 01:28:16.000
So that's, that's sort of how the drug works with lymph nodes. But in general, if you didn't have that spike…

01:28:16.000 --> 01:28:23.000
you know most people within the first two, three, four months are going to have a really nice downward trend.

01:28:23.000 --> 01:28:26.000
Not everybody gets...

01:28:26.000 --> 01:28:48.000
down totally in the normal ranges, so you might, you might sit above normal and as long as it's stable and your lymph nodes are under good control, and the lymphocyte count is stable, they don't have to get to normal. We know that BTK inhibitors do not induce deep remissions which is why they're open ended, why you take them as long as they're working.

01:28:48.000 --> 01:28:56.000
We know that if we looked for CLL in your bloodstream, the average person who's on a BTK inhibitor, we can find it.

01:28:56.000 --> 01:29:12.000
You know the CLL is there. It's, it's under control. You know, it's in remission. And those remissions can last years and years and years and years, but they're not, they're not getting people in deep remissions. So as long as your, your white count is stable,..

01:29:12.000 --> 01:29:19.000
it, it trended down and then it stays stable, that's, that's okay.

01:29:19.000 --> 01:29:23.000
This one's pretty easy. What is considered a retreatment?

01:29:23.000 --> 01:29:30.000
Retreatment is when you repeat a therapy that has been used before. So,..

01:29:30.000 --> 01:29:36.000
someone talked about ibrutinib with venetoclax, the CAPTIVATE study.

01:29:36.000 --> 01:29:38.000
And, and…

01:29:38.000 --> 01:29:42.000
and even with venetoclax and obinutuzumab,..

01:29:42.000 --> 01:29:48.000
patients get, can get treated again with a venetoclax-based regimens and do well.

01:29:48.000 --> 01:30:10.000
In the solid tumor world, that is really rarely done, because people, once they stop responding to something, they don't respond, you know, they don't respond again. But in CLL, we can go back to some of these treatments that aren't toxic now we, when we only had chemotherapy, we didn't go back to chemotherapy. But with these targeted drugs that are well tolerated,..

01:30:10.000 --> 01:30:14.000
we can go back to them. That's retreatment.

01:30:14.000 --> 01:30:18.000
Should blood sodium levels be checked regularly?

01:30:18.000 --> 01:30:24.000
So, when you're getting a comprehensive panel that's getting checked and that's a very frequent,..

01:30:24.000 --> 01:30:27.000
frequently…

01:30:27.000 --> 01:30:33.000
monitored lab for people with CLL, a comprehensive panel.

01:30:33.000 --> 01:30:38.000

I see this question all the time when patients are in treatment and they get to…

01:30:38.000 --> 01:30:40.000
undetectable MRD...

01:30:40.000 --> 01:30:43.000
and then they say, well, so now,..

01:30:43.000 --> 01:30:50.000
is my immune system going to recover?

01:30:50.000 --> 01:30:53.000
You can have undetectable...

01:30:53.000 --> 01:31:00.000
measurable disease and have low IgG levels, they're not, they're not, they don't go hand in hand.

01:31:00.000 --> 01:31:15.000
You know, you're, if your neutrophil count recovers and your IgG levels are good, then your immune system is in good shape. But they don't have to, they don't have to trend that way together. The neutrophils and the IgG…

01:31:15.000 --> 01:31:19.000
levels don't have to trend together.

01:31:19.000 --> 01:31:25.000
Okay, bone pain. Is bone pain an issue with...

01:31:25.000 --> 01:31:27.000
CLL and…

01:31:27.000 --> 01:31:30.000
is there any treatment for bone pain?

01:31:30.000 --> 01:31:40.000
So I have a, I have a whole lot of questions there. So on treatment or off treatment, with growth factor without growth factor, so yes,...

01:31:40.000 --> 01:31:48.000
bone pain can be seen with CLL. It is not a, it's not a common disease...

01:31:48.000 --> 01:31:50.000

related…

01:31:50.000 --> 01:31:56.000
issue like it is with the acute leukemias, where you know the bone marrow is, you know,..

01:31:56.000 --> 01:32:02.000
the, those cells are overturning every 24 hours or every 12 hours. Those people have a lot of bone pain.

01:32:02.000 --> 01:32:08.000
CLL, because it's chronic, there's not as much bone pain. That's not a, a…

01:32:08.000 --> 01:32:11.000
hugely common issue. It can happen.

01:32:11.000 --> 01:32:32.000
But many of our treatments can cause bone pain. The BTK inhibitors can cause bone and joint and muscle aches and pains. And we know that if people get pegfilgrastim or Neulasta or any of those growth factors, those cause bone pain as well.

01:32:32.000 --> 01:32:36.000
What about getting supplements like IV iron...

01:32:36.000 --> 01:32:38.000
or B12 shots?

01:32:38.000 --> 01:32:40.000
So, if your levels are low,..

01:32:40.000 --> 01:32:45.000
yes, getting, getting those supplemented, yes is,..

01:32:45.000 --> 01:32:54.000
is perfectly adequate, yes. And there was an ASH abstract, you know, essentially…

01:32:54.000 --> 01:33:01.000
promoting more IV iron use in in patients with low iron levels.

01:33:01.000 --> 01:33:08.000
Many times with CLL, it's not iron deficiency anemia. People are anemic because their bone marrow is not making…

01:33:08.000 --> 01:33:25.000
you know, red blood cells. It's not because of iron deficiency. So, I don't want everybody out there to start iron infusions. But if you do have an iron deficiency, iron infusions may be appropriate, and, and other B12 as well. If your levels are, are low…

01:33:25.000 --> 01:33:30.000
this one applies to probably a lot of people.

01:33:30.000 --> 01:33:37.000
Is there a problem with drinking coffee?

01:33:37.000 --> 01:33:38.000
Okay.

01:33:38.000 --> 01:33:48.000
I would never tell anyone not to drink coffer unless it nauseates you, unless it gives you like terrible heartburn. If you're on a BTK inhibitor, it can cause, they can cause diarrhea so sometimes,..

01:33:48.000 --> 01:33:53.000
you know, the coffee will aggravate GI symptoms or…

01:33:53.000 --> 01:33:58.000
you know, everybody's different, but I don't want to tell people not to drink coffee.

01:33:58.000 --> 01:34:03.000
So let's carry this one, one step further. And what about energy drinks?

01:34:03.000 --> 01:34:05.000
Oh! Oh!

01:34:05.000 --> 01:34:09.000
Every single thing that I've seen on those...

01:34:09.000 --> 01:34:18.000
say that they're horrible for you. There's data coming out that there's like cyanide in them. They're just, that's they're not…

01:34:18.000 --> 01:34:21.000
I, I don't, I don't recommend energy drinks.

01:34:21.000 --> 01:34:22.000
Yeah.

01:34:22.000 --> 01:34:26.000
Okay. Somebody asked about a, a medicine…

01:34:26.000 --> 01:34:29.000
that they can have on hand if they get the flu.

01:34:29.000 --> 01:34:31.000
And I, I believe this Tamiflu.

01:34:31.000 --> 01:34:35.000
And do you guys prescribe Tamiflu to people to have on hand?

01:34:35.000 --> 01:34:38.000
We do not, we do not…

01:34:38.000 --> 01:34:44.000
prescribe it to have on hand because we want people to be tested and make sure that you have the flu and,.....

01:34:44.000 --> 01:34:50.000
you know, go to, go to your urgent care. And yeah, Tamiflu is definitely...

01:34:50.000 --> 01:35:00.000
appropriate if you do have, have the flu and Paxlovid as well if you develop COVID, and they're effective if, if they're given quickly. So...

01:35:00.000 --> 01:35:01.000
right,..

01:35:01.000 --> 01:35:16.000
you know, if you're having, you know, upper respiratory infection or symptoms sorry, for more than a few days, get tested, you know. You know, if you have a COVID test at home test, you know, go get, go, get tested for flu so that you can get those…

01:35:16.000 --> 01:35:20.000
they're antiviral medications that, that limit the…

01:35:20.000 --> 01:35:25.000
severity and the length of time that you have symptoms.

01:35:25.000 --> 01:35:30.000
This person was asking about the blood donation question again.

01:35:30.000 --> 01:35:33.000
If, if they are in remission,..

01:35:33.000 --> 01:35:34.000
can they donate blood?

01:35:34.000 --> 01:35:35.000
No, no.

01:35:35.000 --> 01:35:37.000
Same, same situation.

01:35:37.000 --> 01:35:38.000
Yeah.

01:35:38.000 --> 01:35:44.000
Yeah, we are getting really close to the end of the event here, and I,..

01:35:44.000 --> 01:35:50.000
I just want to quickly go through and see…

01:35:50.000 --> 01:35:54.000
if there's anything that is real that we could answer…

01:35:54.000 --> 01:35:56.000
quickly.

01:35:56.000 --> 01:35:57.000
See.

01:35:57.000 --> 01:36:03.000
I know there are a lot of people on here Terry. And I just I want to say to everybody,..

01:36:03.000 --> 01:36:06.000
I wish I could have gotten to all your questions.

01:36:06.000 --> 01:36:07.000
Alright!

01:36:07.000 --> 01:36:23.000

Write them down. Take them with you. Ask everyone, every question you have, your primary care, your oncologists. If you have cardiologists, vascular, your endocrinologists ask, write your questions down and get your questions answered everywhere you go.

01:36:23.000 --> 01:36:24.000
Right, right.

01:36:24.000 --> 01:36:27.000
You deserve answers to every single question that you have.

01:36:27.000 --> 01:36:29.000
Right, right.

01:36:29.000 --> 01:36:39.000
There's a question about the person had shingles, and says, should I still get the shingles vaccine?

01:36:39.000 --> 01:36:40.000
Yes.

01:36:40.000 --> 01:36:41.000
And I believe the answer to that is, yes. After the shingles has passed,..

01:36:41.000 --> 01:36:44.000
you should still get the shingles vaccine...

01:36:44.000 --> 01:36:46.000
because it's shown to be very effective.

01:36:46.000 --> 01:36:49.000
I've had shingles three times, and it…

01:36:49.000 --> 01:36:50.000
Yes.

01:36:50.000 --> 01:36:53.000
It is not fun to go through, believe me.

01:36:53.000 --> 01:36:54.000
Yes.

01:36:54.000 --> 01:37:03.000

So let's see if I can get to just, is there any relationship between blood type and CLL, like A or B or O, or?

01:37:03.000 --> 01:37:04.000
there's not.

01:37:04.000 --> 01:37:05.000
Okay. Okay.

01:37:05.000 --> 01:37:06.000
There's not.

01:37:06.000 --> 01:37:12.000
Alrighty! Let's see.

01:37:12.000 --> 01:37:14.000
My dermatologist wants me to do...

01:37:14.000 --> 01:37:20.000
derma therapy, photodynamic therapy to clear up my face from pre-cancerous growth.

01:37:20.000 --> 01:37:23.000
Do you think that that is okay with CLL?

01:37:23.000 --> 01:37:26.000
Yes, I do. Yep.

01:37:26.000 --> 01:37:27.000
Okay.

01:37:27.000 --> 01:37:37.000
And the only, the only time that those things are not okay is if you're on active therapy, if you're on treatment, or you've just finished treatment. You should ask your oncologist if you should wait, you know, a few months.

01:37:37.000 --> 01:37:38.000
Okay.

01:37:38.000 --> 01:37:41.000
But you're not on treatment. Yep.

01:37:41.000 --> 01:37:47.000

All right, Amy. I think we've reached the end of our time here, but I want to ask you to provide any…

01:37:47.000 --> 01:37:50.000
closing thoughts you have for patients and...

01:37:50.000 --> 01:37:57.000
caregivers that have joined the session today. We were well up over 350 people at one point in time.

01:37:57.000 --> 01:38:27.000
Yeah, that's wonderful. I just, I thank you all for being here. Write your questions down, see your specialists, keep yourself healthy. It is not just about your CLL. And also please understand that when you go to see your oncologist they are not thinking about when you had your colonoscopy, what your cholesterol level is, what, when you had your last PSA.

01:38:35.000 --> 01:38:36.000
Right.

01:38:36.000 --> 01:38:41.000
We're not thinking about that at all. We are laser focused on your CLL and so it, it is all your other healthcare providers that are keeping all these other systems healthy that we've been talking about, and there are more. We just touched the, the tip of the iceberg with the health maintenance. But just because you're seeing your oncology team all the time does not mean you're getting comprehensive healthcare.

01:38:41.000 --> 01:38:42.000
So, yeah.

01:38:42.000 --> 01:38:44.000
That's a great point.

01:38:44.000 --> 01:38:45.000
That's a great point.

01:38:45.000 --> 01:38:56.000
Yes, but thank you and everyone for being here. And thank you, Terry and I just want to thank the CLL Society for organizing this as well.

01:38:56.000 --> 01:39:07.000

Well, yeah, you gave a great presentation today. And I want to thank our generous donors and grant support from AstraZeneca, BeiGene, and Genentech, for helping us provide…

01:39:07.000 --> 01:39:17.000
programs like this because they're always usually very well attended and I think very informative for patients.

01:39:17.000 --> 01:39:23.000
And so, I think that we really appreciate you…

01:39:23.000 --> 01:39:28.000
coming to this. We'd like to have you fill out…

01:39:28.000 --> 01:39:31.000
the post event survey to know what we can do better...

01:39:31.000 --> 01:39:37.000
or what topics you would like to see more detail on.

01:39:37.000 --> 01:39:40.000
If you have questions that you really want an answer to,..

01:39:40.000 --> 01:39:43.000
you can send an email to

01:39:43.000 --> 01:39:47.000
Ask the Expert at CLL Society org.

01:39:47.000 --> 01:39:52.000
And then those questions could get answered to you specifically.

01:39:52.000 --> 01:39:55.000
Join us for our next webinar…

01:39:55.000 --> 01:40:01.000
which is getting the most from your CLL treatment, managing side effects, and knowing when to stop…

01:40:01.000 --> 01:40:04.000
which will be on October 16th.

01:40:04.000 --> 01:40:09.000

And the CLL Society has invested in your long life.

01:40:09.000 --> 01:40:11.000
Please invest in the long life…

01:40:11.000 --> 01:40:14.000
of the CLL Society...

01:40:14.000 --> 01:40:17.000
by supporting our work.

01:40:17.000 --> 01:40:22.000
And we want you to be strong, and, as Brian says, we are all in this together.

01:40:22.000 --> 01:40:30.000
Thank you very much.