Virtual Event Transcript
Ask Me Anything – Featuring Dr. Meghan C. Thompson and Michele Nadeem-Baker
November 19, 2025

In science and medicine, information is constantly changing and may become out-of-date as new data emerge.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

This text is based on a computer-generated transcript and has been compiled and edited. However, it will not accurately capture everything that was said on the webinar. The complete recording of this webinar is available on-demand.

00:09:50.000 --> 00:09:58.000
Welcome, everyone. I am Michele Nadeem-Baker, CLL patient and advocate.

00:09:58.000 --> 00:10:05.000
We are live with CLL Society's Ask Me Anything, a virtual event where we will spend the next 60 minutes answering your questions with a CLL expert, and we are so lucky to have Dr. Meghan Thompson from Memorial Sloan Kettering joining us today.

00:10:17.000 --> 00:10:24.000
There is no prepared presentation. This event is dedicated to you and your questions.

00:10:24.000 --> 00:10:29.000
So, ask them away early to make sure that we get to all of them.

00:10:29.000 --> 00:10:43.000
Please use the Zoom Q&A, which is down towards the bottom of your screen, to send your Q&A in the Q&A box, and your questions will come to us, and we'll answer as many as possible.

00:10:43.000 --> 00:10:57.000
Before we begin, I have an important disclaimer to share. Nothing said today should be taken as medical advice. Any questions about your own health and treatment should be discussed with your healthcare provider.

00:10:57.000 --> 00:11:04.000
Without any further ado, Dr. Thompson, would you please introduce yourself for our audience?

00:11:04.000 --> 00:11:15.000

Hi, everyone! Thank you so much, uh, Michele, for the introduction, and the CLL Society for this event. I'm really excited to be here with you all today.

00:11:15.000 --> 00:11:20.000
I'm Meghan Thompson from Memorial Sloan Kettering Cancer Center in New York.

00:11:20.000 --> 00:11:29.000
Um, and I focus my clinical practice on CLL as well as clinical research and clinical trials in CLL.

00:11:29.000 --> 00:11:38.000
Um, and really looking forward to hearing your questions and answering them and having a great conversation this afternoon.

00:11:38.000 --> 00:11:47.000
Thank you. And now for our first question, and hold on, everyone, we have quite a few in already, and from those of you who sent them…

00:11:47.000 --> 00:11:56.000
earlier for us to include. So, for those of us approaching treatment, Dr. Thompson, for the first time, otherwise known as frontline treatment,..

00:11:56.000 --> 00:12:03.000
can you please review the time-limited options for treatment of CLL?

00:12:03.000 --> 00:12:13.000
Yeah, absolutely. And you know, one of the things about CLL is that, um, as many, um, on the call, the patients know,..

00:12:13.000 --> 00:12:24.000
you know, not everyone with CLL needs treatment. There’re certain criteria, including symptoms, other laboratory parameters like your hemoglobin and platelet blood count,..

00:12:24.000 --> 00:12:31.000
um, and then, um, things like enlarged lymph nodes or your spleen being enlarged, so there has to be a reason to treat the CLL.

00:12:31.000 --> 00:12:40.000
And, um, relevant to this question is, usually it is a gradual process, so one of the things I would recommend is…

00:12:40.000 --> 00:12:48.000

um, you know, having these discussions over the course, often they can be had over multiple visits, so I think it's really good…

00:12:48.000 --> 00:12:53.000
um, that we talk about this now. Um, the treatments as of…

00:12:53.000 --> 00:13:04.000
November 2025, I'll kind of go through. So, there's kind of two major pathways, um, there's a continuous pathway, and that traditionally has been the drugs, the BTK inhibitors.

00:13:04.000 --> 00:13:16.000
But focusing on fixed duration, the approved by the FDA fixed duration regimen in the United States is venetoclax, which is a pill-based targeted therapy...

00:13:16.000 --> 00:13:23.000
um, in combination with an IV infusion that's kind of like an early immunotherapy infusion called obinutuzumab.

00:13:23.000 --> 00:13:32.000
And as this regimen is given in a standard fashion, it's about one year of what we call fixed duration or time-limited treatment.

00:13:32.000 --> 00:13:41.000
Um, you get, uh, six cycles, which is about once a month of obinutuzumab, there's a couple other doses up front,..

00:13:41.000 --> 00:13:50.000
um, uh, and then, uh, the venetoclax is for one year. So, that's the main time-limited treatment we've had.

00:13:50.000 --> 00:13:51.000
But over the, yeah.

00:13:51.000 --> 00:13:56.000
Now, is that, is that the one that would give us, have the most promise for a deeper and more durable remission?

00:13:56.000 --> 00:14:05.000
Yeah, great point, Michelle. So, um, at the end of this treatment, many patients actually are in a deep remission.

00:14:05.000 --> 00:14:11.000

Um, and many patients, actually, when we do a really sensitive blood test called minimal residual disease testing,..

00:14:11.000 --> 00:14:17.000
we actually can't detect the CLL cells in the blood, even with a very sensitive test.

00:14:17.000 --> 00:14:25.000
Um, we don't, um, at this point think that it's a curative treatment option, meaning that the CLL...

00:14:25.000 --> 00:14:33.000
um, does tend to come back over time, although there's patients that have years and years of remission. It's about a 6-year…

00:14:33.000 --> 00:14:45.000
average from starting the treatment to the CLL progressing again, but at the end of this treatment, many patients are in a deep remission and then can have several years off of treatment.

00:14:45.000 --> 00:14:46.000
That's one.

00:14:46.000 --> 00:14:54.000
We do have, yeah, one of the things I wanted to mention, though, that you might begin hearing about is there are some other emerging options.

00:14:54.000 --> 00:15:12.000
Um, and so, um, over the past year, a clinical trial last, or kind of annual big American Society of Hematology meeting is upcoming in December and happens every December, and a lot of new studies are presented, and there was a study that was presented…

00:15:12.000 --> 00:15:21.000
that actually looked at combining, um, a BTK inhibitor pill with a venetoclax pill for a pill-pill combination,..

00:15:21.000 --> 00:15:35.000
um, and this is acalabrutinib and venetoclax. This is not approved by the FDA currently. It is, however, listed in our National Comprehensive Cancer Network guidelines, or NCCN guidelines,..

00:15:35.000 --> 00:15:46.000

um, and so it is a treatment option that your physician may discuss for you, and it is a time-limited or fixed duration treatment option. It's a little bit over a year,…

00:15:46.000 --> 00:15:57.000
um, of treatment. Um, and then there's actually, along that same vein, not approved by the FDA currently, but based off that same clinical trial,

00:15:57.000 --> 00:16:08.000
listed in our National Comprehensive Cancer Network guidelines, is acalabrutinib, so BTK inhibitor, venetoclax, and obinutuzumab.

00:16:08.000 --> 00:16:12.000
Now, there's different risks and benefits with these treatment options…

00:16:12.000 --> 00:16:26.000
based on certain CLL characteristics, other medical issues, your doctor will kind of talk you through the pros and cons, but I just wanted to bring up those newer options that I think you'll be hearing more about in the future.

00:16:26.000 --> 00:16:35.000
Can you please contrast those? With the use of continuous therapy, which would be the BTK...

00:16:35.000 --> 00:16:42.000
inhibitors and also maybe could you explain what BTKi means?

00:16:42.000 --> 00:16:52.000
Yeah, absolutely. So, what are, let's start with what, uh, BTK is, because this comes up a lot, um, and there's,..

00:16:52.000 --> 00:17:01.000
um, BTK inhibitors are standard treatments, there's clinical trials of drugs called BTK degraders, so you keep hearing this, this BTK,..

00:17:01.000 --> 00:17:05.000
um, uh, word. And what BTK is, is it's a key...

00:17:05.000 --> 00:17:13.000
pathway in the CLL cells, um, that through signaling or communication,..

00:17:13.000 --> 00:17:18.000
um, this pathway helps the CLL cells grow and survive.

00:17:18.000 --> 00:17:30.000
And so, BTK inhibitors actually block this pathway, and by doing so are able to prevent the growth of CLL cells.

00:17:30.000 --> 00:17:48.000
So, they're a type of what we call targeted therapy, um, where they're pill-based treatments that actually target a really important process that the CLL cells use to live and survive, and these, um, uh, drugs actually kind of turn that off.

00:17:48.000 --> 00:17:57.000
Um, as you mentioned, um, Michelle, these are given continuously as they're approved currently by the FDA.

00:17:57.000 --> 00:18:02.000
Um, and so, um, these days we're often using drugs like acalabrutinib…

00:18:02.000 --> 00:18:10.000
or zanubrutinib that are very, very effective pills. you know, for example,..

00:18:10.000 --> 00:18:19.000
um, at six years of treatment on the acalabrutinib pill, about 70% of patients, the CLL's still in a remission and doing well.

00:18:19.000 --> 00:18:35.000
So, people can be in a remission with these medicines for years and years. However, they work in a very different way than that pill infusion combination, or even the pill-pill combinations, and so the intent of the treatment is to continue it…

00:18:35.000 --> 00:18:46.000
either until it stops working or, of course, if a patient had a side effect that was bothersome, that would also be a reason to discontinue the medicine.

00:18:46.000 --> 00:19:01.000
They are two different approaches. Um, it's really patient-specific. There's pros and cons to each. BTK inhibitors are very convenient. In general, they're very well tolerated and easy to administer…

00:19:01.000 --> 00:19:09.000
um, and certain features of the CLL might point your doctor towards a BTK inhibitor. Having said that,..

00:19:09.000 --> 00:19:17.000

they are a continuous medicine, and so the side effect can be cumulative over time, and also, from a patient perspective, being on treatment,..

00:19:17.000 --> 00:19:24.000
you know, for a prolonged period of time is also something to take into consideration.

00:19:24.000 --> 00:19:31.000
As someone who's been on, um, this is my second time on a BTK inhibitor, because it worked so well the first time,..

00:19:31.000 --> 00:19:39.000
I just, uh, went over the four-year mark, and it'd be nice to have a break in treatment someday.

00:19:39.000 --> 00:19:45.000
And I'm also hoping things don't start to, uh, for, I hope they continue to work, for all of you out there.

00:19:45.000 --> 00:19:53.000
I know that they have worked for others for quite a long time. So, um, so you mentioned a triplet. So, we have another question.

00:19:53.000 --> 00:19:58.000
Um, can you review the used triplet-targeted therapies together?

00:19:58.000 --> 00:20:10.000
And you had talked a little bit about this, and whether they are showing promise for deeper and more durable remissions. I mean, why add on additional drugs? Have you prescribed these as a frontline treatment?

00:20:10.000 --> 00:20:16.000
Yeah, that's a, um, great question, Michelle, and this is a really evolving area.

00:20:16.000 --> 00:20:23.000
Um, as you mentioned, many patients do well with just one drug alone, can be very, very effective, and so,..

00:20:23.000 --> 00:20:31.000
um, the thought of adding, you know, multiple drugs or three drugs, I think is, there's a couple of thoughts behind it.

00:20:31.000 --> 00:20:39.000

So, one is to, for patients who prefer that time-limited approach, to try to get patients into a very deep remission…

00:20:39.000 --> 00:20:50.000
so that time off treatment, um, can be potentially longer. Um, the other is that CLL is very different for different patients, and some patients have,..

00:20:50.000 --> 00:20:59.000
um, different, um, kind of genetic makeup of their CLL that perhaps using a more intensive approach…

00:20:59.000 --> 00:21:08.000
makes sense. Um, we really, I will say, you know, the triplet, just to explain kind of that terminology again, is...

00:21:08.000 --> 00:21:12.000
a BTK inhibitor, a drug like venetoclax,...

00:21:12.000 --> 00:21:18.000
um, which is called a BCL2 inhibitor, it's kind of its class of targeted therapy,..

00:21:18.000 --> 00:21:21.000
um, and then this IV infusion obinutuzumab, which is...

00:21:21.000 --> 00:21:32.000
um, uh, again, an antibody treatment. I think of it like an early immunotherapy type treatment and it targets a protein on the surface of the CLL cells.

00:21:32.000 --> 00:21:47.000
Um, and these have been combined and shown promise in clinical trials. It's actually not currently FDA approved. We do list them in the National Comprehensive Cancer Network guidelines, so it is an option that, you know, might be available to you.

00:21:47.000 --> 00:21:53.000
Um, but one of the things, we do see very promising results with the triplet,..

00:21:53.000 --> 00:21:59.000
um, I think it certainly leads, it appears, that kind of,..

00:21:59.000 --> 00:22:08.000
um, we have less follow-up, or less time that we've been using the triplet, but it certainly appears that many patients are able to get into that deep remission.

00:22:08.000 --> 00:22:17.000
There can be a trade-off in terms of infection risk with it is one of the major things, so more drugs, the more potential for side effects,..

00:22:17.000 --> 00:22:26.000
um, and so it really depends on um, your uh, specific, uh, treatment…

00:22:26.000 --> 00:22:40.000
um, uh, goals, as well as kind of your doctor's assessment of your other medical issues and the risk for infection, and kind of weighing those pros and cons in the discussion with your doctor.

00:22:40.000 --> 00:22:50.000
I've been part of clinical trials, um, so at Memorial Sloan Kettering, we've had a clinical trial with the triplet, and so I do have experience using it, and I think it works...

00:22:50.000 --> 00:22:57.000
um, you know, well for patients, but CLL is not a one-size-fits-all approach, so I think...

00:22:57.000 --> 00:23:13.000
and facing that decision, it's good to think through, well, what would the potential side effects and potential kind of pathway of treatment and time on treatment look like with a triplet versus BTK inhibitor versus a venetoclax-based treatment?

00:23:13.000 --> 00:23:19.000
So, you were talking about making the decisions for which therapy is best for a patient.

00:23:19.000 --> 00:23:24.000
So, what are the key considerations from a medical point of view? You mentioned...

00:23:24.000 --> 00:23:28.000
medical history, but what types of things would you be looking for?

00:23:28.000 --> 00:23:39.000
Yeah, um, I think always thinking about, um, uh, cardiovascular or heart side effects is important because, um,..

00:23:39.000 --> 00:23:44.000
for any regimen, you kind of want to know what the baseline heart function is.

00:23:44.000 --> 00:23:52.000
But the BTK inhibitors in particular, do, over time have a high risk of increased blood pressure,..

00:23:52.000 --> 00:23:58.000
um, and so, for example, if it's been difficult to control blood pressure, maybe...

00:23:58.000 --> 00:24:05.000
veering towards another option if there's another option, like venetoclax might be advisable.

00:24:05.000 --> 00:24:12.000
Or there's about a 5-15% chance with the BTK inhibitors of a heart arrhythmia called atrial fibrillation,..

00:24:12.000 --> 00:24:35.000
so still, you know, happens in few patients on a BTK inhibitor, but if there's a history of a cardiac arrhythmia, it doesn't mean you can't use a BTK inhibitor, but I just do engage with the patient's cardiologist, primary care physician, to think about those things. Venetoclax has its own set of risks, and so there's a risk of something called tumor lysis syndrome with venetoclax...

00:24:35.000 --> 00:24:45.000
which I think about that, like, basically the venetoclax is so effective at first that it bursts open the CLL cells, it can release potassium, it can affect the kidneys.

00:24:45.000 --> 00:24:51.000
We have many methods actually, to prevent this, so that's a very rare thing to happen.

00:24:51.000 --> 00:24:59.000
But, you're higher risk if your lymph nodes are bigger or if your kidney function is a little decreased. So really weighing those...

00:24:59.000 --> 00:25:08.000
parts of the medical history, and then thinking about the CLL, there's different mutations or genetic features of the CLL,..

00:25:08.000 --> 00:25:20.000
you know, it's not that one mutation means you get one treatment, we're definitely not at that point in CLL, but all these kind of factors come into play, or you have really big lymph node,..

00:25:20.000 --> 00:25:30.000
um, some people might have that, and this tumor lysis syndrome risk might be a little better, you might have to go to the hospital for a dose.

00:25:30.000 --> 00:25:37.000
It’s all these factors kind of come into play, and then the logistical considerations, there's different monitoring,..

00:25:37.000 --> 00:25:42.000
you know, required on treatment, and we really want to make sure the CLL treatment is feasible,..

00:25:42.000 --> 00:25:47.000
um, for patients' lives and quality of life and things like that.

00:25:47.000 --> 00:25:51.000
Can I just, uh, reflect on something you just said? So,..

00:25:51.000 --> 00:26:01.000
we are at a point that's just so different than when many of us were first diagnosed with CLL, and that's that we do have these choices. And to ask our doctors,..

00:26:01.000 --> 00:26:07.000
um, if they can guide us in which treatment may be best for us, it wasn't like that not all that long ago,..

00:26:07.000 --> 00:26:11.000
where there, you know, there was one gold standard, and it was...

00:26:11.000 --> 00:26:18.000
chemotherapy, too, combined with something else, you know, so we really are in a great time.

00:26:18.000 --> 00:26:27.000
And it's getting better, hopefully, with CLL. Um, which brings me to a question someone asked, and that is, is...

00:26:27.000 --> 00:26:32.000
is there any speculation you have on how long before there's a cure?

00:26:32.000 --> 00:26:38.000
Oh, wow, it's such a good question. I think, you know,..

00:26:38.000 --> 00:26:55.000
the CLL, as you mentioned, Michele, has just really drastically changed for the better, really year by year. I think we're going to be, um, if we do this program a year from now, we'll be talking, uh, even different, even potentially in the frontline setting, so,..

00:26:55.000 --> 00:27:00.000
um, there's been two FDA approvals for CLL over the past,..

00:27:00.000 --> 00:27:05.000
um, two years of drugs. And there's many more drugs in development.

00:27:05.000 --> 00:27:11.000
When we talk about cure, that is the goal of CLL research, right?

00:27:11.000 --> 00:27:21.000
But I think one of the tough parts, and I think we're going to hit on this, um, in, uh, some of the other questions that were submitted by…

00:27:21.000 --> 00:27:26.000
patients is that for CLL, there's treating the cancer...

00:27:26.000 --> 00:27:31.000
and then we know that with CLL, there's also the increased risk of infection…

00:27:31.000 --> 00:27:41.000
and a slightly increased risk of other cancers, such as skin cancers and other malignancies. So, when we think about cure, it's both…

00:27:41.000 --> 00:27:49.000
getting rid of the cancer, but also, you know, functionally making sure the infection risk isn't increased and things like that.

00:27:49.000 --> 00:27:55.000
And so, those are the two main things. I think we're doing a great job at getting rid of this CLL.

00:27:55.000 --> 00:28:08.000
Um, but one of the research focuses, I think, um, is also making sure that with our treatment, we're not increasing the risk of infection or future side effects, too. So, I can't put a timeline on it.

00:28:08.000 --> 00:28:11.000
But I'm really, really hopeful with some of the…

00:28:11.000 --> 00:28:22.000
combinations of these targeted pill-based therapies with some of the newer immune-based therapies that we have in development.

00:28:22.000 --> 00:28:25.000
And I do want to, you know, bring up...

00:28:25.000 --> 00:28:29.000
that patients with CLL, there've been studies done now...

00:28:29.000 --> 00:28:36.000
that when we use the treatments we have available in 2025, looking at CLL patients...

00:28:36.000 --> 00:28:41.000
and patients without CLL in a general population study,..

00:28:41.000 --> 00:28:48.000
the, uh, lifespan does not appear to be significantly different, so we aren't at the point of cure right now…

00:28:48.000 --> 00:29:00.000
but we are at the point of managing the disease. But a lot of research going on that hopefully, we do get to that point where there's one treatment and we're rid of the CLL.

00:29:00.000 --> 00:29:13.000
Well, I look forward to the cure as you defined it. A lot of us experience infections pretty frequently, and that would be, I mean, all of what you said is music to many of our ears here.

00:29:13.000 --> 00:29:20.000
Uh, since patients with SLL have much less CLL in the blood, and it's more, um,..

00:29:20.000 --> 00:29:31.000
it would be more lymph node burden, does blood-based MRD testing for SLL patients…

00:29:32.000 --> 00:29:38.000
actually reflect the load? And have studies compared SLL-MRD with CLL results with the same markers? Great question.

00:29:38.000 --> 00:29:48.000
What a great question. I have the same question. Um, so I think this is, like, hitting on, um, some of the research that's going on now.

00:29:48.000 --> 00:30:02.000

So, you know, for patients with SLL, as long as they do have some detectable cells in the blood, which in most cases, almost all cases they do, we can use this MRD, or minimal residual disease testing.

00:30:02.000 --> 00:30:11.000
Um, but the point is a really good one, that sometimes patients, even when we can't detect CLL in the blood,..

00:30:11.000 --> 00:30:25.000
they finished the treatment, they're in a remission, they're feeling great, and maybe the lymph node is still a little enlarged, and this question comes up, is it just a scarred lymph node or are there still some cells there? Is this test really good?

00:30:25.000 --> 00:30:29.000
I think on the whole, the test is pretty good, because…

00:30:29.000 --> 00:30:38.000
um, we know that there're patients from studies who've had, you know, maybe a little enlarged lymph node still when they stop the treatment…

00:30:38.000 --> 00:30:44.000
and they're undetectable in the blood, and in general, that they still have a very long remission.

00:30:44.000 --> 00:30:51.000
There are some newer tests, though, that aren't available outside of a clinical trial, but researchers are working on.

00:30:51.000 --> 00:31:10.000
Um, to look at, um, tests called circulating tumor DNA that actually is a different, it's a blood test still, but it actually looks for cells shed from the SLL in the lymph nodes, or even if you have CLL, the CLL and the lymph nodes.

00:31:10.000 --> 00:31:18.000
Um, and that might be a better measure of the lymph node disease and is a blood test that is being monitored.

00:31:18.000 --> 00:31:25.000
It's not clear yet from the research that's been done that that's better, though, than the blood MRD test.

00:31:25.000 --> 00:31:35.000

But I would say stay tuned, and um, what a thoughtful, um, question that I think we'll learn more about in the coming years.

00:31:35.000 --> 00:31:42.000
We have a series of questions that follow onto the BTKi discussion.

00:31:42.000 --> 00:31:50.000
And here's one of them. This patient says, I have CLL and have been on acalabrutinib for nearly six years.

00:31:50.000 --> 00:31:58.000
My hematologist says guidelines don't suggest taking patients off of it, so that would be continuous treatment.

00:31:58.000 --> 00:32:06.000
Yet a recent webinar physician claimed her patients continue to do well after they stopped taking it.

00:32:06.000 --> 00:32:10.000
Can you explain what the practices are?

00:32:10.000 --> 00:32:15.000
Yeah, this is a really, I think, question that applies to so many patients…

00:32:15.000 --> 00:32:19.000
and it is also an area we're learning more and more about.

00:32:19.000 --> 00:32:37.000
Um, I'd say, again, CLL is very heterogeneous or different in different patients, um, so it really depends on your circumstance. There are, you know, as it's approved in studies, it's a continuous treatment,..

00:32:37.000 --> 00:32:44.000
um, and, um, there are some patients that will, tor example,..

00:32:44.000 --> 00:32:50.000
your CLL might just be very sensitive to the BTK inhibitor if you're a patient with CLL, and…

00:32:50.000 --> 00:32:57.000
if you maybe stop your BTK inhibitor because you're having a procedure that has an increased risk of bleeding,..

00:32:57.000 --> 00:33:08.000
you know, sometimes patients will actually get symptoms stopping their BTK inhibitor, and it doesn't agree with, it doesn't mean their CLL is out of control, but it just doesn't agree with them to be off the medicine.

00:33:08.000 --> 00:33:19.000
Um, but we actually know from clinical trial, there are some patients that actually do fine when they stop the BTK inhibitor, so we never really planned to stop it in general, but…

00:33:19.000 --> 00:33:22.000
sometimes things come up. So, what's an example of that?

00:33:22.000 --> 00:33:29.000
So, say you're on the medicine, and you have a new side effect on the medicine...

00:33:29.000 --> 00:33:34.000
and the CLL is under good control, oftentimes, this means you've been on the...

00:33:34.000 --> 00:33:41.000
BTK inhibitor for a couple of years, the CLL is under control, a side effect comes up...

00:33:41.000 --> 00:33:53.000
and patients stop the medicine. Or, um, something happens where, um, unfortunately, in some cases, access to the medicine has been an issue.

00:33:53.000 --> 00:34:01.000
Um, and we, you know, um, there's a lot of programs to work on that, but it has happened, and I've seen that, unfortunately, happen.

00:34:01.000 --> 00:34:07.000
Um, and there's two clinical trials, actually, that shed some light on, like, what one can expect.

00:34:07.000 --> 00:34:15.000
So, one is, um, there was a clinical trial of actually ibrutinib, which is an earlier BTK, the first BTK inhibitor,..

00:34:15.000 --> 00:34:24.000
um, and patients who stop for reasons other than the BTK inhibitor stopping working, so the CLL is under control, but they stopped.

00:34:24.000 --> 00:34:36.000

They hadn't planned to stop, but something happened, and they stopped it. Um, there was actually about two and a half years before the CLL progressed, on average.

00:34:36.000 --> 00:34:43.000
Now, there was a wide range to that. Some people weren't able to be off the BTK inhibitor, for some people it was longer than two years before they needed treatment again.

00:34:43.000 --> 00:34:49.000
So, there are cases with patients where they've stopped for another reason...

00:34:49.000 --> 00:35:02.000
whether it be a side effect, they had an infection, there's something else going on medically, um, where I do reassess the CLL at that time point, and sometimes we discuss it and do decide,..

00:35:02.000 --> 00:35:09.000
um, to, um, not resume the BTK inhibitor and do careful monitoring.

00:35:09.000 --> 00:35:12.000
And then at our center at Memorial Sloan Kettering, um,..

00:35:12.000 --> 00:35:19.000
we have a clinical trial, um, where we gave the BTK inhibitor acalabrutinib,..

00:35:19.000 --> 00:35:28.000
um, patients did get obinutuzumab for six months with the acalabrutinib, so it wasn't just a BTK inhibitor alone.

00:35:28.000 --> 00:35:41.000
Um, and patients were able to stop early if they were undetectable minimal residual disease if we couldn't detect the CLL cells after one year, but then actually everyone on the study stopped the BTK inhibitor after two years.

00:35:41.000 --> 00:35:46.000
Um, and so we're still learning, um, what the experience is from this trial, but I can...

00:35:46.000 --> 00:35:52.000
share that it was an average of about two years. Again, that seems to be the mark…

00:35:52.000 --> 00:35:57.000
where patients were able to have what we call a time off treatment.

00:35:57.000 --> 00:36:12.000
So, I do think we're going to see more and more, um, data from patients where maybe a break is feasible. It might not be for everybody, but I think it's something to talk to your doctor about.

00:36:12.000 --> 00:36:20.000
Um, someone else asked this other question. So, if a patient goes on a time-limited treatment…

00:36:20.000 --> 00:36:26.000
with a BTKI combination, um, which would be what, actually, what you were just talking about,..

00:36:26.000 --> 00:36:36.000
um, can they use a BTK inhibitor alone if and when they relapse as a second line of treatment?

00:36:36.000 --> 00:36:44.000
Yeah, these are such great questions. Um, uh, it's like a perfect segue into what we were just talking about.

00:36:44.000 --> 00:36:57.000
Um, I think, um, in most cases, yes, um, I think you always, how I always approach it with the patient is, you know, why did we stop the treatment in the first place?

00:36:57.000 --> 00:37:02.000
If it was, like, a really bad side effect that we think you're going to experience again...

00:37:02.000 --> 00:37:09.000
or, to be honest, is going to impact your quality of life again, and we don't want to go back there, and we have another option...

00:37:09.000 --> 00:37:15.000
and maybe we don't do a BTK inhibitor again, but if it was, like, some other reason,..

00:37:15.000 --> 00:37:25.000
um, like it was a minor side effect, or there was an infection, or some sort of procedure, or other medical issue that came up that led us to do that in the first place, or it was a…

00:37:25.000 --> 00:37:32.000
minor side effect, you know, there is, um, some limited,..

00:37:32.000 --> 00:37:38.000

albeit limited data, but there's no reason to think that you couldn't use the BTK inhibitor alone again.

00:37:38.000 --> 00:37:48.000
Um, and for patients who got, um, BTK inhibitor and venetoclax, there's some studies that are coming out now showing that exactly what you've brought up,..

00:37:48.000 --> 00:37:56.000
um, does work and people respond. So, um, definitely, definitely an option.

00:37:56.000 --> 00:38:01.000
Is there a process for coming off of acalabrutinib…

00:38:01.000 --> 00:38:07.000
with monitoring and are there pros and cons to being monitored or not being monitored, or…

00:38:07.000 --> 00:38:09.000
a process, so to speak?

00:38:09.000 --> 00:38:17.000
Yeah, I mean, again, outside of a clinical trial, it's not really standard, it's not in the guidelines.

00:38:17.000 --> 00:38:27.000
So, there's no protocol, I would say. Um, but for the patients where, say, they've had a side effect and we stop the acalabrutinib, for example,..

00:38:27.000 --> 00:38:38.000
um, I do kind of closer monitoring, um, in terms of, you know, making sure there's no growing lymph nodes on the physical examination,..

00:38:38.000 --> 00:38:45.000
maybe a little bit more frequent blood work than we were doing on the treatment, depending on the patient situation.,.

00:38:45.000 --> 00:39:02.000
um, uh, to monitor. Um, but I'd say it's still an area that's mostly being developed in clinical trials, so there's not a standard, and it would need to be personalized to you with your doctor.

00:39:02.000 --> 00:39:10.000

How critical is a karyotype? And maybe you can explain that in your answer, and do the recommended treatments differ from...

00:39:10.000 --> 00:39:18.000
those who are at the highest CLL, uh, risk? And is there a difference in overall survival for those...

00:39:18.000 --> 00:39:21.000
with a karyotype?

00:39:21.000 --> 00:39:37.000
Yeah, so a karyotype, um, just to explain, is when, actually, the, all of, and this is referring to the genetics of the CLL cells specifically, so, like,..

00:39:37.000 --> 00:39:43.000
not the genes that, ,.so we all have karyotypes or genetics that we were born with.

00:39:43.000 --> 00:39:51.000
um, but this is looking at the cancer cells and what can be done is looking at all the chromosomes, which contain,..

00:39:51.000 --> 00:39:56.000
um, the genetics of your cancer cells is how you can think about it.

00:39:56.000 --> 00:40:04.000
And there's certain abnormalities in the chromosomes that we know are common with CLL.

00:40:04.000 --> 00:40:14.000
And those are done often by a testing called FISH testing, so some of you might have heard of deletion 13Q, or deletion 17P.

00:40:14.000 --> 00:40:34.000
So that's kind of specific focus chromosomal testing. A karyotype is actually when, um, a process is done, and CLL is very slow growing, that in the laboratory, they actually stimulate the CLL cells. They have to get them to grow faster, and then they look at the cells in different phases,..

00:40:34.000 --> 00:40:43.000
um, and then they look at all the chromosomes and look for, um, changes from what we call normal karyotype, or there's a way that...

00:40:43.000 --> 00:41:09.000

the chromosomes normally look. So, um, it, in CLL, um, doing this, um, and every, uh, institution does it differently, so at Memorial Sloan Kettering, we actually don't do what's called a karyotype on the peripheral blood, we do something called SNP array analysis, but we do a karyotype on the bone marrow, so there's a lot of, like, technicalities involved, but in general,..

00:41:09.000 --> 00:41:26.000
um, if you have a karyotype done, if there's five or more abnormalities in the chromosomes of your CLL cells, that's considered to be higher risk. It used to be defined as three or more, but it seems like actually five is probably a more accurate number.

00:41:26.000 --> 00:41:34.000
You know, it's a risk. But it doesn't mean that treatments won't be effective,..

00:41:34.000 --> 00:41:39.000
um, and so it's just one piece to the puzzle.

00:41:39.000 --> 00:41:45.000
It is testing that you should ask your doctor about doing before starting treatment…

00:41:45.000 --> 00:41:53.000
because it won't necessarily change the treatment, um, at least not in 2025 that you receive.

00:41:53.000 --> 00:42:07.000
But it could help your doctor give you a sense of what the likely time on that treatment is, or time before the next treatment is, or length of remission, and things like that.

00:42:07.000 --> 00:42:11.000
Here's a general question. Um, is it better to do...

00:42:11.000 --> 00:42:15.000
time-limited therapy or to take treatment…

00:42:15.000 --> 00:42:20.000
ongoing until no longer tolerated or relapsed?

00:42:20.000 --> 00:42:37.000
Yeah, what a great question. I don't know the answer to that, because there really hasn't been, there's been a couple of clinical trials, but there's been no definitive clinical trial using the drugs we use, you know, today in 2025, even in 2024…

00:42:37.000 --> 00:42:50.000
that have looked at, like, continuous versus time limited. Um, there is a study that's going to be presented in just a couple weeks at that big, uh, United States American Society of Hematology meeting…

00:42:50.000 --> 00:42:55.000
that is going to look at patients who are treated with continuous ibrutinib…

00:42:55.000 --> 00:43:05.000
versus time limited venetoclax obinutuzumab, and then ibrutinib venetoclax, so, um, the results of that study, I think, will be informative.

00:43:05.000 --> 00:43:22.000
However, it's really hard, because we're not using ibrutinib tends to have more side effects than acalabrutinib, zanubrutinib, and so it's not exactly, maybe, the regimens we're talking about, but that study could help kind of answer this question in some ways.

00:43:22.000 --> 00:43:48.000
And then the genetic features are also, you know, potentially at play here, so, um, there's some thought that maybe patients with p53 mutation may be a continuous regimen is better, but this is based off of a very small number of patients, and again, there's no definitive clinical trial, so it really needs to be personalized to the patient's case and all these factors.

00:43:48.000 --> 00:43:57.000
Um, but that's one of the reasons, it's a good problem to have in a way in CLL that we have so many options.

00:43:57.000 --> 00:44:04.000
Um, but it is, I understand, you know, it does make for this treatment decision,..

00:44:04.000 --> 00:44:12.000
um, to have, I really view it as an opportunity to really review in detail, often over the course of several visits, you know, what,..

00:44:12.000 --> 00:44:17.000
what the treatment options are, and what would be the best fit for,..

00:44:17.000 --> 00:44:24.000
you know, you as a patient, um, and also your CLL characteristics.

00:44:24.000 --> 00:44:28.000
Next question has to do with AIHA,..

00:44:28.000 --> 00:44:40.000
um, which should be great in your answer if you can explain what that is for our audience. So, a recent study showed benefit from stopping BTKi's in terms of quality of life...

00:44:40.000 --> 00:44:53.000
if a CLL patient is tied to AIHA, hemolytic anemia, would the patient expect to see the same benefit or does the link to AIHA make a difference?

00:44:53.000 --> 00:45:04.000
Um, in both scenarios, what's the best strategy for monitoring the progression-free status? Wow, what a loaded question there.

00:45:05.000 --> 00:45:16.000
Yeah, yeah, that's a complicated, uh, question for sure. So, yeah, let's, let's, yeah, let's talk about Michele, I think your point, so, um, AIHA is, as Michele mentioned, is hemolytic anemia...

00:45:16.000 --> 00:45:29.000
with the AI is autoimmune hemolytic anemia, so, um, this is something that can happen in patients without CLL...

00:45:29.000 --> 00:45:40.000
Where, but it's more common, it's very, it's quite common, and it doesn't happen to all CLL patients, but it's not an uncommon occurrence in patients with CLL…

00:45:40.000 --> 00:45:51.000
where your immune system actually makes antibodies and you're destroying your red blood cells, and so the hemoglobin goes low,...

00:45:51.000 --> 00:45:59.000
um, and you can be anemic. And this is thought in CLL patients to be driven by the underlying CLL.

00:45:59.000 --> 00:46:06.000
Um, and so it's, if you've heard of autoimmune diseases, you know, CLL is the cancer of the immune system.

00:46:06.000 --> 00:46:15.000
Um, and then there's other autoimmune diseases. Autoimmune hemolytic anemia is a process that is really like an autoimmune disease where your...

00:46:15.000 --> 00:46:24.000
body's producing antibodies that are destroying red blood cells, and when you're anemic, you can become tired, the hemoglobin can go low.

00:46:24.000 --> 00:46:29.000
Um, and so there's a couple of different, actually, treatment approaches to this.

00:46:29.000 --> 00:46:35.000
Um, some patients with autoimmune hemolytic anemia and CLL,...

00:46:35.000 --> 00:46:44.000
um, can initially get treatments like steroids. Um, sometimes you'll get treatments like infusions like rituximab,..

00:46:44.000 --> 00:46:47.000
um, and sometimes they don't need a BTK inhibitor.

00:46:47.000 --> 00:46:57.000
Other patients, um, the process of these antibodies destroying the red blood cells might be more difficult to occur...

00:46:57.000 --> 00:47:01.000
or patients might have gotten steroids before, and it comes back again…

00:47:01.000 --> 00:47:11.000
and, um, it's very manageable in most cases, this autoimmune hemolytic anemia, but it is disruptive to be wondering, is it going to come back again, and so…

00:47:11.000 --> 00:47:19.000
BTK inhibitors are often a treatment that are used, especially after steroids and rituximab, for,…

00:47:19.000 --> 00:47:30.000
um, autoimmune hemolytic anemia. I don't know of any data specifically on looking at patients…

00:47:30.000 --> 00:47:39.000
with CLL, being treated with BTK inhibitors with a history of the autoimmune hemolytic anemia and what happens when they stop the BTK inhibitor.

00:47:39.000 --> 00:47:44.000
I would think that, just based on, kind of, my clinical experience…

00:47:44.000 --> 00:47:52.000
that there is a higher risk of the autoimmune hemolytic anemia recurring if you do stop the BTK inhibitor.

00:47:52.000 --> 00:48:04.000
But I, I will say it's not something I've commonly, I've, we see the autoimmune hemolytic anemia, but I haven't had many patients stop or seen research on that, so that's…

00:48:04.000 --> 00:48:09.000
maybe an understudied area that we need to learn more about.

00:48:09.000 --> 00:48:18.000
If I experienced atrial fibrillation from acalabrutinib or another BTK inhibitor, it's sent,..

00:48:18.000 --> 00:48:22.000
well, it sent this patient to the hospital, and now it's controlled.

00:48:22.000 --> 00:48:27.000
Is it safe to continue with, let's say, acalabrutinib or Zanubrutinib…

00:48:27.000 --> 00:48:32.000
as it appears to be working, uh, for the CLL?.

00:48:32.000 --> 00:48:48.000
Yeah, this is a great question. It does come up all the time, um, uh, so, in general, yes, if the atrial fibrillation is well controlled, I always kind of check with the cardiologist,..

00:48:48.000 --> 00:49:01.000
um, about the status of the atrial fibrillation, make sure there's a plan for medical management of it. You know, sometimes there was another provoking, you know, certainly the BTK inhibitors increased this risk,..

00:49:01.000 --> 00:49:07.000
um, but there can be other factors, like an infection, like a pneumonia can increase,..

00:49:07.000 --> 00:49:17.000
can be kind of an acute trigger for the atrial fibrillation as well, so making sure those other things are optimized and under control.

00:49:17.000 --> 00:49:25.000
And then heart arrhythmias can be incredibly complicated, and so, um, just making sure that there's no other,..

00:49:25.000 --> 00:49:37.000
um, uh, risk factors, the cardiologist is noting, kind of on their evaluation before restarting. There are some cases where, when those other risk factors are present…

00:49:37.000 --> 00:49:48.000
that might be a time to consider, especially if the CLL is under good control, um, this re-evaluation, and whether, um, maybe a break could be warranted.

00:49:48.000 --> 00:50:11.000
Um, in cases where the CLL, you know, would benefit from further treatment in the immediate moment, um, I think there are some cases where you might switch to something like venetoclax, just to not have to worry, you know, once you have atrial fibrillation, there's a risk of future atrial fibrillation, BTK inhibitor or not, and so following with the cardiologist either way is important.

00:50:11.000 --> 00:50:28.000
You could go the venetoclax route. If that's an option, or there are patients who can safely go on the, back on the BTK inhibitor, um, the oncologist, uh, cardiologist work together. So a lot of, a lot of different potential options there, something that comes up a bit.

00:50:28.000 --> 00:50:37.000
Wow, we have, we haven't even gotten through half of our questions, and we have 81 more questions that have come in live. I wish we could spend more than...

00:50:37.000 --> 00:50:45.000
I believe, we have an hour only. I wish I could go and fast-forward here, but let's try, wow.

00:50:45.000 --> 00:50:54.000
This patient has had pain in their spleen area for 10 months and it's worsening, but the doctor says their spleen is not enlarged because he can feel it.

00:50:54.000 --> 00:50:58.000
What may be going on?

00:50:58.000 --> 00:51:07.000
So there's pain, let me make sure I understand, there's pain in the spleen area, in the spleen area, so your spleen's on your left side.

00:51:07.000 --> 00:51:14.000
But the spleen on the physical examination was not thought to be enlarged.

00:51:14.000 --> 00:51:15.000
Okay. Yeah, that's a, that's, um, an interesting, uh,..

00:51:15.000 --> 00:51:19.000
Correct.

00:51:19.000 --> 00:51:41.000
case, I would say those are sometimes cases where we don't always do, and I know patients had questions about imaging, scans, so maybe we can address that a little bit with this question too. So, we don't always do imaging, like, on, you know, there's some cancers where maybe you get a CAT scan every six months.

00:51:41.000 --> 00:51:53.000
Um, routinely, um, when not on treatment or after treatment, and so in CLL, it's often driven by symptoms, and so this might be a case where I would start with an ultrasound.

00:51:53.000 --> 00:52:07.000
Um, and then consider, um, depending on the symptoms, exam, um, if it's really persistent pain, things like, um, a CAT scan might be, might be an appropriate next step.

00:52:07.000 --> 00:52:15.000
Um, you know, there's other organs in that area, too, so sometimes it could be a gastrointestinal,..

00:52:15.000 --> 00:52:22.000
um, issue, um, and so seeing a gastroenterologist, sometimes they do, like, a scope, like an upper endoscopy,..

00:52:22.000 --> 00:52:31.000
um, which is similar to a colonoscopy, but looking in your esophagus and stomach, um, to see if it could be a reason unrelated to the CLL.

00:52:31.000 --> 00:52:52.000
Um, very rarely patients can get something like a splenic infarction, but usually that's when the spleen is enlarged, so, um, would be good to talk to your doctor about, you know, other potential, um, gastroenterology or maybe doing an ultrasound or even CAT scan.

00:52:52.000 --> 00:53:00.000
Uh, what is the significance in treatment and prognosis of elevated monoclonal IgG?

00:53:00.000 --> 00:53:07.000
Kappa free light chains that continue to climb without significant elevation of ALC.

00:53:07.000 --> 00:53:12.000
Are these coming from antibody-secreting cells?

00:53:12.000 --> 00:53:21.000
And if so, what are they? So, there's a lot to unpack in here.

.

00:53:22.000 --> 00:53:33.000
Yeah, that's a really, uh, advance, like, sophisticated question. Um, so, I think, you know, this is how I would think about it. I mean, I can't answer it without seeing the laboratory work, because basically…

00:53:33.000 --> 00:53:42.000
what is IgG? Let's talk about that. So, IgG is a blood test that many of you may get with your doctor at some point or another.

00:53:42.000 --> 00:53:55.000
Um, and it measures, it's called immunoglobulin G, and it's a marker of antibody production and your B cells are the cells in your body that produce antibodies.

00:53:55.000 --> 00:53:59.000
And in patients with CLL, they often actually have low IgG.

00:53:59.000 --> 00:54:08.000
Um, and so some of you might have heard of something called IVIG, or intravenous immunoglobulin, which is sometimes,.

00:54:08.000 --> 00:54:18.000
um, given to patients to prevent infections if they've had serious infections and have low levels. This question is asking about high IgG.

00:54:18.000 --> 00:54:26.000
And there are some cases where the CLL can produce extra IgG.

00:54:26.000 --> 00:54:34.000
And to figure out if this is related to the CLL...

00:54:34.000 --> 00:54:48.000

or this is another process, um, it's a little bit of a pathology question, and it looks at surface markers on the CLL by a test called flow cytometry…

00:54:48.000 --> 00:54:57.000
and then it looks, you can look, do special tests called immunofixation and protein electrophoresis on this IgG protein.

00:54:57.000 --> 00:55:05.000
So, it's very complicated and patient-specific, and then sometimes you can have polyclonal IgG. What does that mean?

00:55:05.000 --> 00:55:11.000
You know, with an autoimmune disease, you could get IgG, so there's many reasons behind that, but I would say…

00:55:11.000 --> 00:55:19.000
for that patient, I would ask your doctor about whether the protein's been tested.

00:55:19.000 --> 00:55:40.000
Um, in and of itself, um, IgG typically, um, is not, um, such a problem to be elevated, but in some patients it is a marker of the activity of the CLL, and you can also have high IgM. Some of you might have heard of that, that's another type of antibody.

00:55:40.000 --> 00:55:45.000
Um, but there's other things that can cause that as well.

00:55:45.000 --> 00:55:53.000
We just have, I mean, people here are really smart about their CLL. We have a very educated audience here, the CLL Society.

00:55:53.000 --> 00:55:59.000
Uh, just so, I don't even know where to go here. We have so many with not much time left.

00:55:59.000 --> 00:56:08.000
Let's switch quickly to preventing infections and lifestyle, and we, it's that time of year…

00:56:08.000 --> 00:56:15.000
for the flu and, you know. more prominent numbers of COVID and RSV, so...

00:56:15.000 --> 00:56:19.000
trying to summarize a lot of what these questions say.

00:56:19.000 --> 00:56:31.000
Uh, what vaccines do you recommend that we all get, and is there any, uh, are there any effects that can have…

00:56:31.000 --> 00:56:39.000
on us and our CLL? Can any of them increase our CLL numbers? Can they make it flare?

00:56:39.000 --> 00:56:42.000
Are there any to stay away from during treatment?

00:56:42.000 --> 00:56:45.000
I think I've now covered all of it here.

00:56:45.000 --> 00:56:57.000
Yeah, these are great questions. So, with CLL being a cancer of the immune system, patients with CLL are at higher risk for infection than patients without CLL.

00:56:57.000 --> 00:56:59.000
Um, we don't have a great, like, blood test,..

00:56:59.000 --> 00:57:07.000
uh, in 2025 to say, you know, how immunocompromised or how much increased infection risk a patient with CLL is.

00:57:07.000 --> 00:57:13.000
Um, and it exists just as CLL does on a little bit of spectrum. So, there's some patients with very…

00:57:13.000 --> 00:57:19.000
frequent infections, and then there's some patients who are less frequently have infection.

00:57:19.000 --> 00:57:20.000
Hmm.

00:57:20.000 --> 00:57:26.000
For all patients, generally, should not receive any live vaccinations.

00:57:26.000 --> 00:57:35.000
Now, there's not many live vaccinations that you would get as an adult, but I always tell patients to reach out, you know, to the office if you're traveling somewhere,..

00:57:35.000 --> 00:57:41.000
um, for example, if the travel doctor recommends vaccines. I do recommend,..

00:57:41.000 --> 00:57:51.000
um, flu vaccine. Um, I, um, uh, recommend, um, the Shingrix vaccine,..

00:57:51.000 --> 00:57:59.000
um, which is a two-part vaccine series. A pneumonia vaccine, um, there's a new one out called Prevnar 21.

00:57:59.000 --> 00:58:11.000
What the timing of that, there's old, older pneumonia vaccines, uh, many of you might have gotten Pneumovax or Prevnar 13 or even Prevnar 20, so that's something to talk to your doctor about based on what you've kind of had already.

00:58:11.000 --> 00:58:19.000
Um, there is, um, an RSV vaccination, um, that, um, is not a live vaccine.

00:58:19.000 --> 00:58:31.000
Um, and then, uh, COVID, uh, vaccination. And, you know, to the question, I guess, about, um, flaring of the CLL,..

00:58:31.000 --> 00:58:39.000
um, you know, there's nothing that we know of with these vaccines that makes the CLL progress faster.

00:58:39.000 --> 00:58:56.000
Are there patients who have a rise in their CLL after getting a vaccination? Yes, but it's very difficult to pinpoint whether that would have happened anyways. One thing that does happen when you get a vaccine, even patients without CLL can get this, are the increase of the little swelling of the lymph nodes right after the vaccine.

00:58:56.000 --> 00:59:09.000
Um, but that's the immune system's response to the vaccine, so that's not unexpected. Um, and so, um, that's something that can come up, but it doesn't necessarily mean the CLL is progressing.

00:59:09.000 --> 00:59:15.000
And then in terms of treatment timing, this is very specific to what…

00:59:15.000 --> 00:59:33.000

treatment, um, you're getting, um, there are, um, you know, certain cases where treatments will make you less likely to respond to the vaccines, and so the timing might be delayed. The best thing, um, if you're able, is to actually get the vaccines before,

00:59:33.000 --> 00:59:39.000
the recommended vaccines, before you start treatment, so if you're on active observation...

00:59:39.000 --> 00:59:50.000
or active surveillance of CLL, um, that's something to kind of check through, um, to see if you're up-to-date on those vaccinations.

00:59:50.000 --> 00:59:54.000
That was great, thank you. Very comprehensive on that.

00:59:54.000 --> 01:00:04.000
Bug bites, I see this all the time, I have it happen to me, it's all the time on our various support groups online...

01:00:04.000 --> 01:00:12.000
so, it seems to be a thing. Is it a thing with CLL patients or is it all just coincidental for all of us?

01:00:12.000 --> 01:00:25.000
No, I think it's definitely something we've observed that, um, for patients who maybe haven't experienced this, because not every patient does, but it does come up.

01:00:25.000 --> 01:00:30.000
Um, that especially in the summer with insects like mosquitoes.

01:00:30.000 --> 01:00:40.000
Many patients will get a mosquito bite and have, like, what we call an exaggerated reaction to it, so there can be a lot, actually, a significant amount of swelling,..

01:00:40.000 --> 01:00:45.000
um, redness, warmth, um, in the area where the bug bite is.

01:00:45.000 --> 01:00:50.000
Um, and so, this is often able to be managed,..

01:00:50.000 --> 01:01:02.000
um, uh, with, um, uh, topical steroid-type treatments. Um, you know, there are some patients who have more severe cases of this…

01:01:02.000 --> 01:01:09.000
or there's patients who maybe, um, have a skin rash and they're not, they have this swelling…

01:01:09.000 --> 01:01:17.000
or these spots crop up, but they don't remember, like, being outside or in an insect area, and they're not sure if it's an insect bite.

01:01:17.000 --> 01:01:25.000
In those cases, I have patients, um, see a dermatologist. There are very rare skin conditions, too, that are associated with CLL,..

01:01:25.000 --> 01:01:32.000
um, and can be managed with different, um, topical treatments, as well as, uh, injection treatments.

01:01:32.000 --> 01:01:45.000
Um, there's something called eosinophilic dermatosis of hematologic malignancy that we see in CLL patients. So, um, definitely if this is coming up, I would bring it up with your CLL doctor.

01:01:45.000 --> 01:01:59.000
Um, and it might be, um, uh, advisable to work with a dermatologist, too, and see if there's any additional strategies to manage this.

01:01:59.000 --> 01:02:05.000
Uh, we have one on sinus staph infections. Is it typical…

01:02:05.000 --> 01:02:13.000
for CLL patients to have them? And is it typical for them to be unresponsive to…

01:02:13.000 --> 01:02:16.000
numerous antibiotics?

01:02:16.000 --> 01:02:24.000
Yeah, um, I think, you know, certainly, there are infections, especially...

01:02:24.000 --> 01:02:35.000
sinus infections, um, pneumonia, respiratory infections, and even skin infections we see at higher incidence, and staph is a common bacteria.

01:02:35.000 --> 01:02:41.000

Um, you know, many patients are responsive to antibiotic therapy.

01:02:41.000 --> 01:02:46.000
Um, it depends a little bit on the specific bacteria,..

01:02:46.000 --> 01:02:58.000
um, where the infection came from, um, you know, there are these cases in patients with and without CLL of resistant bacteria, where sometimes other,..

01:02:58.000 --> 01:03:07.000
um, strategies, um, in terms of alternative antibiotics that maybe aren't as more commonly used, uh, need to be employed. So,..

01:03:07.000 --> 01:03:17.000
I don't know that necessarily staph is more common, or resistant staph is more common, but it is something that may come up.

01:03:17.000 --> 01:03:24.000
Um, the next one is on exercising and...

01:03:24.000 --> 01:03:30.000
higher white blood counts. So, does doing a workout, this particular person runs, they run 6 kilometers at,..

01:03:30.000 --> 01:03:35.000
it's a little over 3.7 miles, does it cause white blood, your white blood count…

01:03:35.000 --> 01:03:40.000
to rise, or is it any exercise? All exercises are just,..

01:03:40.000 --> 01:03:46.000
um, cardio, and how long should someone wait after this type of exercise to have...

01:03:46.000 --> 01:03:48.000
a blood test done?

01:03:48.000 --> 01:03:56.000
Oh, what a great question. I'll admit I don't know the exact answer to it. I think your white blood cell count,..

01:03:56.000 --> 01:04:05.000
uh, can be affected by so many things, you know, in general, in patients with CLL, many of the cells are CLL cells, but,..

01:04:05.000 --> 01:04:16.000
um, inflammation, infection, all these things can affect it, so if the workout is causing some inflammation, it might increase the white blood cell count a little bit.

01:04:16.000 --> 01:04:24.000
Um, that's why I never put too much stock in any one blood value. I think it's all about trend over time, and if there's something…

01:04:24.000 --> 01:04:32.000
really abnormal or unexpected, repeating that, you know, not necessarily immediately, but at some point in the near future,..

01:04:32.000 --> 01:04:37.000
um, is advisable, and I tell patients, you know,..

01:04:37.000 --> 01:04:44.000
and we see this, like, they get their blood checked maybe with another doctor, and then a week later, like, the blood count's a little different.

01:04:44.000 --> 01:04:55.000
And some of that might be that labs are a little different, but it's kind of like we check your blood count on Monday, it's going to be one thing, on Friday it's going to be a little bit different, so it's all about, kind of, over time,..

01:04:55.000 --> 01:05:04.000
um, with CLL, so I don't think you necessarily need to wait, you know, after your workout to check the blood count.

01:05:04.000 --> 01:05:09.000
Uh, some of us are told…

01:05:09.000 --> 01:05:21.000
when we are in remission, what does that mean to our compromised immunity? Can we integrate more into society out to dinner, visit with friends and family with more confidence?

01:05:21.000 --> 01:05:27.000
Um, and will it still take longer to recover from a possible illness?

01:05:27.000 --> 01:05:31.000
Or do we, do we basically, do we still have to keep our guard up…

01:05:31.000 --> 01:05:34.000
or can we go back to everyday activities?

01:05:34.000 --> 01:05:47.000
Yeah, this is a really, uh, important question. I'd say we don't know fully the answer to this question, and it does depend a little bit on what treatment and how long after the treatment it's been.

01:05:47.000 --> 01:05:55.000
Um, there's, you know, maybe some data that while the treatment decreases the immune system,..

01:05:55.000 --> 01:06:04.000
maybe some emerging data at the early phases, it's just understudy right now, that treatment might lead to some immune restoration, um, and so,..

01:06:04.000 --> 01:06:10.000
um, while patients with CLL are always at higher risk for infection,..

01:06:10.000 --> 01:06:20.000
um, my advice is kind of to follow. some common sense guidelines in terms of try to, it's not always feasible, but try to avoid people you know are sick.

01:06:20.000 --> 01:06:27.000
Hand washing, things like that, and then it's really individualized to the patient. Certainly, quality of life,..

01:06:27.000 --> 01:06:35.000
um, being able to visit with friends and family and do activities that are important to you, and this is really my perspective as a,..

01:06:35.000 --> 01:06:45.000
you know, CLL doctor, not necessarily in it, and it's really individualized to the patient, but I do think it's important to be able to do those things that are important to you.

01:06:45.000 --> 01:06:50.000
And then, you know, just keeping in mind, if you know someone's sick, avoid them.

01:06:50.000 --> 01:06:57.000
Um, but hopefully we'll hear more on this, and I think this is a great point to close on in the coming years.

01:06:57.000 --> 01:07:05.000

I think there's a lot of research being done because this, as you mentioned, impacts quality of life and really, um, health as well,..

01:07:05.000 --> 01:07:16.000
um, about infection prevention and, um, how we can restore the immune system. So, I would say stay tuned,..

01:07:16.000 --> 01:07:23.000
um, on this topic, and, um, I'm hopeful that we'll make a lot of progress in kind of understanding the risk,..

01:07:23.000 --> 01:07:29.000
um, and being able to provide more definitive answers in the future.

01:07:29.000 --> 01:07:36.000
Dr. Thompson, this has been great. We need two more hours for all of these questions that are still coming in.

01:07:36.000 --> 01:07:39.000
I hope you can come back and join us again.

01:07:39.000 --> 01:07:47.000
Yeah, I would love to. This has been really, uh, the hour just really flew by. It's really fantastic.

01:07:47.000 --> 01:07:53.000
Um, I loved, uh, hearing what everyone was thinking about…

01:07:53.000 --> 01:07:58.000
and would love to continue the conversation in the future.

01:07:58.000 --> 01:08:05.000
I'm hoping to see you at ASH, but before we close the program, do you have any closing thoughts for our audience?

01:08:05.000 --> 01:08:20.000
Yeah, first, I just want to thank the audience for such great questions. I, it's really, um, I'm always amazed and impressed by, um, the questions asked by our CLL patients.

01:08:20.000 --> 01:08:25.000
Um, and this is really, I just want to…

01:08:25.000 --> 01:08:29.000

tell patients that there's a lot of, you know,..

01:08:29.000 --> 01:08:36.000
right now, in 2025, we have great treatments for the CLL, but there's a lot of exciting new treatments coming out.

01:08:36.000 --> 01:08:54.000
Um, or just refining the way we're giving the existing treatments, which many of you were asking about in your questions, like, okay, we know about BTK inhibitors and venetoclax, but, like, how can we modify how we're giving it? And that's what we're doing in research, um, in collaboration with patients,..

01:08:54.000 --> 01:09:04.000
um, their families, um, and then doctors and laboratory scientists. We're all coming together to refine this, so I'm really excited and hopeful for the future.

01:09:04.000 --> 01:09:10.000
Um, and would, uh, love to do another one of these events. It was great.

01:09:10.000 --> 01:09:17.000
It's been great having you. Thank you so much for your time and your expertise. You weren't throwing any curveballs here.

01:09:17.000 --> 01:09:25.000
We are very grateful for your participation. Um, I just want to thank everyone who joined us today.

01:09:25.000 --> 01:09:34.000
And we'd also like to thank our generous donors to the CLL Society and grant support from Genentech for making this event possible.

01:09:34.000 --> 01:09:42.000
Don't go away yet. Please complete our brief event survey. We really want to hear from you and your feedback.

01:09:42.000 --> 01:09:49.000
And our next webinar for the CLL Society is on January 14th, and that will be...

01:09:49.000 --> 01:09:53.000
everything on ASH 2025, and it's coming to you.

01:09:53.000 --> 01:10:01.000

And you'll be able to learn the breaking CLL research as presented at the American Society of Hematology annual conference, which is in…

01:10:01.000 --> 01:10:20.000
just a couple of weeks, folks. So, if your question was not answered today, please send it to our Ask the Expert email service. This is a free service and can be found on the CLL Society website under Programs and Support. And please remember that the CLL Society is invested in your long life...

01:10:20.000 --> 01:10:26.000
and you can invest in the life, the long life, of the CLL Society by supporting our work.

01:10:26.000 --> 01:10:36.000
For the CLL Society, this is Michele Nadeem-Baker. Thank you so much for being here with us.